

The West Virginia Guide to Accessing Services for Individuals with Autism Spectrum Disorder

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A Product of WV Team Autism



ABOUT WEST VIRGINIA TEAM AUTISM

Autism Spectrum Disorder (ASD) is the fastest growing disability in our nation. Approximately **1 in 68** children have an Autism Spectrum Disorder (CDC, 2014). Every state in the nation is asking "how can we best serve these individuals and their families?" It is the belief of many key players in the area of ASD in the state of West Virginia that the best way to make an impact on services in our state is through the collaboration of existing agencies, systems, and individuals who are dedicated to providing assistance, support and services for those with an Autism Spectrum Disorder. We knew we could make a difference working together. Early on, WV Team Autism identified several critical areas of need in our state:



- 1) providing a system of seamless services for children from 0 to 21,
- 2) providing a continuum of services for adults,
- 3) building effective early intervention programs and
- 4) increasing our capacity for teacher training.

Another critical need identified was the need to help families find the appropriate supports and services they needed as soon after receiving the diagnosis as possible. This guide to accessing resources in West Virginia is one outcome of the collaborative effort to address this critical need.

SPECIAL THANKS

Special thanks to the WV Team Autism committee that worked on the revisions and updates for this document. Your work serves as a testament to your dedication to WV children, teens, adults and families experiencing Autism Spectrum Disorder.

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ABOUT THIS GUIDE

We are pleased to offer you this booklet about services, resources and information for West Virginians with Autism Spectrum Disorder (ASD) and their families. The purpose of this booklet is to help you get started acquiring resources available to you and your child and to gain a better understanding of the educational system in West Virginia. West Virginia Team Autism members recognize, through personal and/or professional experience, the challenges facing families as they learn their child is diagnosed with ASD. We know it can be overwhelming and frustrating to secure the supports and services your child needs. Our goal is to make sure every parent receives the support and guidance they need and that support and guidance are available right from the beginning.

This booklet is intended to be part of the file you have or will have developed to store information so that you can refer back to it as needed. We have included information that families have found helpful as they enter education and other service systems. You will be provided with specific information related to your individual needs and also be given the names of specific contact people in your area. We hope you find this guide a useful tool now and for the future. Updates will be completed in April and October each year. Please note that you will find the terms "autism" and "Autism Spectrum Disorder" used interchangeably.

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Disclaimer:

The purpose of this document is to offer helpful suggestions for families of children diagnosed with Autism Spectrum Disorder as they navigate the service delivery system in West Virginia. It is not the intent of West Virginia Team Autism to recommend any specific service or treatment over any other. This guide aims to provide information on state and other resources and is not intended as a comprehensive guide to all available service providers in all service delivery areas.

Where Do I Start?

Whether families have just received a diagnosis of Autism Spectrum Disorder (ASD) for their child or they have had the diagnosis for several years, there is one thing most families have in common; they are on a journey with different twists and turns, challenges and celebrations. If you are at the beginning of this journey, the amount of information you are receiving is probably overwhelming. It is important to remember that most people cannot absorb everything all at once, nor should they. Every family has different dynamics. Some have multiple children, multiple jobs and may be engaged in a variety of activities outside of the home. Time may be limited. It is OK to access new information related to your child's diagnosis and service options a little at a time. As one parent put it "It's a marathon, not a sprint."

It is also important to know that while individuals with ASD share some common overall characteristics, each individual is completely different from the next. What is effective for one individual may not work at all for another. Each individual has different strengths, abilities, interests and challenges. If there were one prescription for individuals with ASD, we would all be using it. As you begin to investigate service options for your child, never hesitate to reach out to professionals and other parents for their input. Ask questions! Establishing positive relationships with others who understand ASD can make all the difference in the world. But always remember, you are the expert on your child. No one knows your child like you do.

And finally, as you get started on this journey, remember that success IS a journey. There are many tools and resources contained in this guide that we hope will make your journey to success just a little bit easier.

Family Contact Information

Parents/Guardian _____

Child's Name _____ Date of Birth _____

Address _____

Phone – Home _____ Mobile _____ Work _____

Email _____

Is your child and family receiving WV Birth to Three Services? YES NO

Team Member	Role on the Team	Email	Phone
	Service Coordinator		

Is your child receiving public school services? YES NO

Home School _____

Team Member	Role	Email	Phone
	Teacher		

Is your child or family receiving any other services? YES NO

Agency	Service	Email	Phone

This information should be shared with your WV Birth to Three Team and/or County Director of Special Education and the School Based Team. This information would also be beneficial to share with other community agencies supporting your child and family.

Step One:

Learn About Autism Spectrum Disorder

Prior to May, 2013, "autism" was the term commonly used when talking about Autism Spectrum Disorder. "Autistic disorder" was one of five disorders characterized under the heading "Pervasive Developmental Disorders." The other four disorders were "Asperger's Disorder", "Childhood Disintegrative Disorder", "Rett Syndrome" and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)". With the 2013 revision of the Diagnostic Statistical Manual of Mental Disorders (DSM 5) the category "Pervasive Developmental Disorders" was removed. The disorders listed above no longer exist as separate diagnoses on the autism spectrum. Instead (with the exception of Rett's Syndrome, which has become its own entity), they have been merged into the diagnosis of "Autism Spectrum Disorder." Specific qualifiers based on support needs were added. ("Level 1," "Level 2," and "Level 3")

While the appropriate diagnostic term is currently "Autism Spectrum Disorder," you may still hear the term "autism" and "Asperger's Disorder" or "Asperger's Syndrome" used frequently.

The more you know about Autism Spectrum Disorder the better equipped you will be to make informed decisions for your child. Educate yourself about treatment options, ask questions and participate in treatment decisions.

What is Autism Spectrum Disorder?

Autism Spectrum Disorder (ASD) is a complex developmental disability that is the result of a neurological disorder effecting the functioning of the brain. ASD can profoundly impact how the person interacts with the world. Typically appearing during the first three years of life, ASD affects the person's ability to communicate and interact with others. ASD is often referred to as a "spectrum disorder" because the defining diagnostic criteria affect individuals differently and to varying degrees.

Every person with ASD is an individual, and like all individuals, has a unique personality and combination of characteristics. Some individuals may exhibit only slight delays in language and have greater challenges with social interaction. Others may exhibit significant problems in their ability to communicate with others and to tolerate the world around them.

ASD impacts . . .

- the frequency and way the person communicates with others
- how the person interacts with others
- how the person takes in and responds to sensory information
- the number and type of activities the person engages in.

Common characteristics include:

- Lack of or a delay in spoken language
- Repetitive use of language and/or motor mannerisms (e.g. hand flapping or twirling objects)
- Little or no eye contact
- Lack of interest in peer relationships
- Lack of spontaneous or make believe play
- Persistent fixation on parts of objects.

Although we do not have all the answers on the different causes of the Autism Spectrum Disorder, we do know they are treatable. Research studies have shown that early diagnosis and intervention can lead to significantly improved outcomes.

Where can I find more information?

- Autism Speaks - www.autismspeaks.org
- Autism Internet Modules - <http://www.autisminternetmodules.org/>
- The Autism Society – www.autism-society.org

Step Two:

Become the Expert on Your Child!

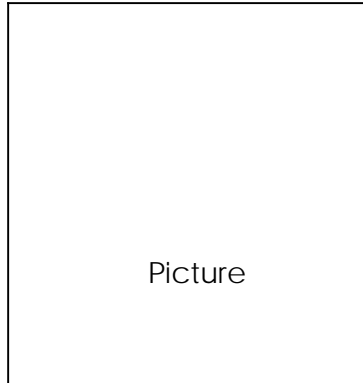
You have a source of knowledge regarding your child that no professional can ever have. You know your child best and communicating this wealth of information within partnerships with professionals can help to ensure that your efforts to support the growth and development of your child are successful.

Figure out what might trigger "disruptive behavior" and what elicits a positive response. What does your child find stressful? What is calming to your child? What is uncomfortable for your child? What is enjoyable? If you understand what affects your child you will become better at solving problems and preventing situations that cause difficulties.

ALL ABOUT ME!

For young children, tweens and teens

Adapted from WV Birth to Three – All About Me



Hi! My Name is _____. I am a pretty big deal! My Parents and I thought you would like to know a little bit about me! If you have any questions, please feel free to ask them. I am sure that I will be busy playing with my favorite things!

My Full Name is: _____ (But my parents only use my full name, when I am in trouble). You can call me: _____ and I am _____ years old.

My best time of day is: _____

My favorite toys are: _____

My favorite food is: _____

I am afraid of: _____

A Bit About My Family:

My Parents/Guardian: _____

My Brothers & Sisters: _____

My Other Family & Friends You Might Want To Know About: _____

My Pets: _____

Things I Love:

1. _____

2. _____

3. _____

Things I Dislike:

1. _____

2. _____

3. _____

Things That Are Challenging For Me:

1. _____

2. _____

3. _____

Things That Motivate Me:

1. _____

2. _____

3. _____

Things You Might See If I get Frustrated:

1. _____

2. _____

3. _____

Things That Calm Me Down When I Get Upset:

1. _____

2. _____

3. _____

How I Communicate:

1. _____

2. _____

3. _____

Important Health Information (Doctor, Allergies, Etc.):

- 1. _____
- 2. _____
- 3. _____

Doctor(s) and Phone(s)

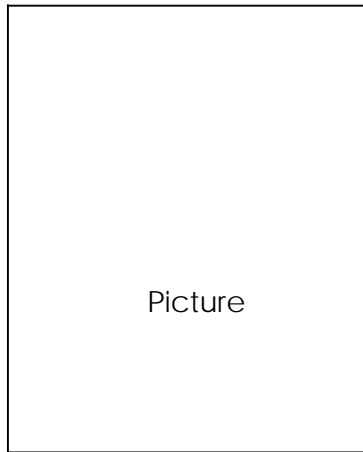
- 1. _____
- 2. _____
- 3. _____

Other Information That Might Be Nice to Know:

- 1. _____
- 2. _____
- 3. _____

A Bit About Me:

For older teens and adults



My name is: _____

I prefer to be called: _____

I usually communicate by: _____

Things I am interested in:

1. _____

2. _____

3. _____

Things that can be challenging for me:

1. _____

2. _____

3. _____

Things I sometimes do if I am upset or frustrated:

1. _____
2. _____
3. _____

Things that help to calm me down:

1. _____
2. _____
3. _____

Important health issues (Doctor, Allergies, Etc.):

1. _____
2. _____
3. _____

Other information that might be nice to know:

1. _____
2. _____
3. _____

My emergency contacts include:

1. _____
2. _____
3. _____

My Contact Information:

Home Phone: _____

Cell Phone(s): _____

Work Phone(s): _____

E-Mail: _____

Home Address: _____

Step Three:

Accept Your Child for Who They Are

Being told your child has ASD can be traumatizing and you may feel stunned by the news. You may also feel a variety of other emotions, like fear, shock, disbelief or despair. Accept those feelings as real and nurture yourself. You will also work to accept your child for who they are . . . the amazing, beautiful and loved being that you cannot imagine life without!

As you are honing your expert on your child skills, and learning more about ASD you will want to begin to apply your knowledge. How does the information about ASD relate to the years of knowledge you have about your child? Taking your time to explore what ASD means to your child and family will begin to help you move forward in considering the most appropriate options.

When you understand how these sets of knowledge work together, you will be building a foundation for yourself as a strong advocate for your child. As you advocate with caring and understanding you will engage with professionals from a variety of service systems, all there under the premise of supporting your child and family. Approach these relationships the way you approach the relationship with your child - be kind, willing to listen and eager to problem solve together. If we do not emulate these positive attitudes then we cannot expect those from others. It is through these parent-professional partnerships that your child will learn and grow, gaining the skills necessary to be an active participant in all aspects of daily life.

The worksheet on the next page can begin to help you to identify specifics, such as:

- How ASD characteristics appear in my child
- Gifts and talents my child has
- Dreams our family has for our child and what they will be able to do.

Thinking deeply about these concepts will assist you in your conversations with the variety of professionals with whom you will be developing partnerships in the care of your child. Remember they will never know the vast amounts of intimate knowledge you have regarding your child and their abilities and challenges. The professionals need you as much as your child does to ensure success in meeting their unique needs.

Remember – you are the expert on your child.

How Does ASD Affect My Child?

Reflect upon the characteristics of Autism Spectrum Disorder and how they affect your child.

Characteristic	What This Might Look Like	How Does My Child Do This
Social Interactions	<ul style="list-style-type: none"> ○ Have difficulty making eye contact with others ○ Show little body language or facial expressions when interacting ○ Have difficulty developing relationships with peers ○ Seem uninterested in sharing experiences ○ Engage less in give-and-take social interaction with caregivers, siblings, and other close relations 	
Speech, Language, and Communication	<ul style="list-style-type: none"> ○ Have difficulty communicating with speech or with gestures ○ Have difficulty understanding what others are saying to him ○ Have difficulty using the language he has to interact with others ○ Have difficulty starting or continuing a conversation ○ Have difficulty using his own sentences, and instead, may repeat what others say (referred to as echolalia) ○ Lack make-believe or pretend play skills 	
Stereotypical or Repetitive Behaviors	<ul style="list-style-type: none"> ○ Show interest in very few objects or activities and pay with them in repetitive ways ○ Perform repetitive routines and have difficult with changes in these routines ○ Spend time in repetitive movements (such as waving a hand in front of his face) 	

Remember to share these points with anyone involved with your child.

Step Four:

Enjoy Your Child and Celebrate Small Successes

If you show joy with your child and their accomplishments, facing the world openly with a smile your positive example can lead others to have a positive and joyful approach.

Milestones are an achievement, not just an item on a list

When you have a child with ASD you learn to appreciate the milestones, both big and small. Some would say that we celebrate a little too much for such little accomplishments but I'd argue that we celebrate accordingly, its other parents who take them for granted.

First words, learning to walk, swimming, riding a bike, reading, writing... all these things that make parents proud are far more than just steps along the way when your child has ASD... they're cause for celebration.

Take nothing for granted

Along the same lines, but very different from milestones, is taking nothing for granted. Unless you have a child with ASD (or another disability like it), you'll probably never know what it's like to be lucky enough to be hugged one time a year.

Does your child look you in the eye? If your child has ASD, maybe not. Does your child give you a hug or kiss sometimes? If your child has ASD, maybe not.

You will never ever realize just how much the tiniest little things can be so extremely important until they're not there.

Patience, more than you ever thought possible

The biggest problem with milestones is that everyone knows what they are and when they should happen so when your child is missing them, everyone says something. It's hard; it's oh so very hard.

After a while though, you develop a thicker skin... not just the patience required to take their "advice" a little better but also to have the patience and self-confidence in knowing that if you never give up on your children, the milestones will come.

The beauty that is around us

The world around us moves pretty fast and can be so filled with sights and sounds that it turns into a bit of a blurry mess. Our mind makes it that way to keep us from becoming overwhelmed, crazy and tired. We filter through a lot of everything that goes on in our daily lives without really realizing it.

Many people, especially the children, with ASD don't have the same filtering capabilities and often times do get overwhelmed by it all. This often results in meltdowns or even violence.

You, as the parent, become increasingly aware of the world around you because you have to, because you need to know what you are getting your child into. Loud restaurants, carnivals, movie theaters... many places can be far too difficult for your child to be able to process and you need to be aware of that before the fact.

As you develop this ability over time, it forces you to slow down and truly appreciate the sights and smells and sounds that surround us every single day.

You go outside and there isn't a car in the neighborhood... it's so very peaceful. Before you likely never would have noticed, much less enjoyed that feeling of peace, because your mind builds that filter in place before you ever go out and so you don't notice if there are cars or not.

Your child is perfect because of whom they are

It isn't until others see your child as flawed, and worse, until you start to see your own child as flawed, that you can learn what is truly important... not a disability, not a disorder, not even a gift... a child is who they are inside and who they are inside is exactly who they are supposed to be... your child.

It's ok if no one will ever look at your child the same way you do, they're not supposed to. Our children are amazing human beings with unlimited potential.

The difference

Celebrate the differences, not just in your child, but in yourself. For better or worse, you've become a better person for it; you've become a better parent. Your child isn't like other children... and that seems hard to take but honestly, before your child was born, and you saw how "other children" are on the news or in movies... is that really what you wished for when you imagined having a child? For them to be like all the others?

No, none of us want our children to have it harder than anyone else, and no we don't want our children to suffer... but many of us recognize that we can have these thoughts and these feelings while still being able to recognize and celebrate the differences.

Your child is amazing.

You are amazing

Celebrate it ... you've earned it.

Duncan, S. (2011). *Let me tell you a little about celebrating Autism Spectrum Disorder*. Retrieved from <http://www.autismsupportnetwork.com/news/let-me-tell-you-little-about-celebrating-autism-33899232>.

Step Five:

Don't Give Up!

Children with ASD have an entire lifetime to grow and increase their abilities, just like every other child! Don't jump to conclusions that your child will not be able to do certain things! It may feel overwhelming when you think of everything your child needs to learn but every day individuals with ASD show the world what they can overcome, compensate for and otherwise manage what is challenging for them. Use the partnerships you have with professionals and other families to equip yourself with information, strategies and connections to support your child on their journey toward independence.

Find Nonverbal Ways to Connect

Connecting with your child can be challenging, but you don't need to talk in order to communicate and bond. You communicate by the way you look at your child, the way you touch him/her, and by the tone of your voice and body language. Your child is also communicating with you, even if he/she never speaks. You just need to learn the language!

- **Look for cues** – If you are observant and aware you can learn to pick up on the nonverbal cues that children with ASD use to communicate. Pay attention to the kinds of sounds they make, their facial expressions, and the gestures they use when they are hungry, tired, or want something.
- **Figure out the need behind the tantrum** - it's only natural to feel upset when you are misunderstood or ignored, and it's no different for children with ASD. When children with ASD act out, it's often because you're not picking up on their nonverbal cues. Throwing a tantrum is their way communicating their frustration and getting your attention.
- **Make time for fun.** A child coping with ASD is still a kid. For both children with ASD and their parents, there needs to be more to life than therapy. Schedule playtime when your child is most alert and awake. Figure out ways to have fun together by thinking about the things that make your child smile, laugh, and come out of their shell. Your child is likely to enjoy these activities most if they don't seem therapeutic or educational. There are tremendous benefits that result from your enjoyment of your child's company and from your child's enjoyment of spending unpressured time with you. Play is an essential part of learning and shouldn't feel like work.
- **Pay attention to your child's sensory sensitivities.** Many children with ASD are hypersensitive to light, sound, touch, taste, and smell. Other children with ASD are "under-sensitive" to sensory stimuli. Figure out what sights, sounds, smells, movements, and tactile sensations trigger your kid's "bad" or disruptive behaviors and what elicits a positive response. If you understand what affects your child, you'll be better at troubleshooting problems, preventing situations that cause difficulties, and creating successful experiences.

- What does your child find stressful or overwhelming?

- What does your child find calming?

- What does your child find enjoyable?

Use what you know about your child to think about other strategies that might help you and your child connect as well. Think about these:

- **When giving your child instructions/directions . . .**
 - Come to me,
 - Get my attention, and
 - Speak in plain, simple words (i.e., Wyatt put your car in the bucket, its bath time.)

- **Speak in clear words** – I need you to be very specific when you are talking with me. Saying 'hold your horses' is confusing; tell me you need me to 'stop running'. Don't tell me something is 'easy as pie' when there is no pie in sight; tell me 'this will be easy for you'.

- **I'm visually oriented**
 - Show me how to do things rather than telling me and be prepared to show me many times.
 - Using visual supports will help me understand what comes next during the day and will relieve stress for both of us. That will make our days run much more smoothly!
 - Visual supports might include visual schedules, photos, and cue cards
 - Where you can go to learn more:
 - Visual Supports –
 - Autism Spectrum Disorder Speaks - <http://www.autismspeaks.org/science-resources-programs/autism-treatment-network/tools-you-can-use/visual-supports>
 - Autism Internet Modules - <http://www.autisminternetmodules.org/>
 - National Professional Development Center on Autism Spectrum Disorder Spectrum Disorders – www.autismnow.org
 - Tips for Creating Visuals – Center on Social Emotional Foundations of Early Learning - <http://csefel.vanderbilt.edu/modules/module3b/handout2.pdf>
 - Visual schedules –
 - Hands in Autism Spectrum Disorder Interdisciplinary Training and Resource Center - www.handsinautism.org
 - Document discussing development and use of visual schedules (provides a wide variety of photographed examples) – www.handsinautism.org
 - Visual Cues
 - First/Then Board – <http://www.autismclassroomnews.com/2013/05/visual-schedule-series-first-then.html>
 - <http://lessonpix.com/articles/9/35/First+Then+Boards>
 - Activity System –
 - <http://www.autisminternetmodules.org/>
 - <http://www.iidc.indiana.edu/?pageId=416>

- **I want to be successful!** Focus on what I can do rather than what I cannot do. Like anyone I will avoid doing things that make me feel inadequate or inept. Use my strengths to help me find a way to accomplish things in a different way.

- **I want to interact with family and peers!** I need you to teach me how to play and communicate with others.
 - I rely on you for support, guidance and love. You will help me be successful!
 - Encourage others to invite me to play along
 - Start with my favorite games and then teach me how to do new things
 - Focus on structured activities that have a clear beginning and end.

Adapted from Smith, M., Segal, J., Hutman, T (2013). *Helping children with Autism Spectrum Disorder: Autism Spectrum Disorder treatment strategies and parenting tips*. Retrieved from <http://www.helpguide.org/mental/autismhelp.htm>.

Step Six:

Be Consistent

Children with ASD have a hard time adapting what they learn the first time. Be consistent in your child's environment to reinforce learning. Find out what your child's teachers and therapists are doing and incorporate those into the home environment. Be consistent with the way you interact with your child and dealing with any challenging behaviors.

Provide Structure and Safety

Learning all you can about Autism Spectrum Disorder and getting involved in treatment will go a long way toward helping your child. Additionally, the following tips will make daily home life easier for both you and your autistic child:

Stick to a schedule:

Children with ASD need structure and routine. Set up a schedule for your child, with regular meals, therapy time, bath time, bed time. Try to keep disruptions to a minimum. If there is a schedule change, try and prepare your child in advance for it. (See links and information on page 20 for visual supports)

Reward good behavior:

Positive reinforcement can go a long way. Praise your child when they have good behavior or learn a new skill. Be very specific about what behavior they are being rewarded for. Look for other ways to reward them by giving a favorite toy or a favorite item they like. Helpful links:

- Pyramid Model for Supporting Challenging Behavior
 - http://www.challengingbehavior.org/do/pyramid_model.htm
 - <http://www.challengingbehavior.org/communities/families.htm>
 - <http://csefel.vanderbilt.edu/resources/family.html>
- Autism Spectrum Disorder Speaks Challenging Behavior Tool Kit - http://www.autismspeaks.org/sites/default/files/challenging_behaviors_tool_kit.pdf
- Prompting – <http://www.friendshipcircle.org/blog/2013/04/22/a-complete-guide-for-using-prompts-to-teach-individuals-with-special-needs/>
- Reinforcement – <http://www.educateautism.com/behavioural-principles/positive-reinforcement.html>

Create a home safe zone:

Create a private space in your home where your child can go to relax, feel secure, and be safe. This will involve organization and setting boundaries in ways that your child can understand. You can use visual cues to help your child understand a safe zone for them; labeling items, using colored tape to mark off areas or visual schedules as a strategy to keep your child happy and safe. For some children you may need to safety proof the house, particularly if your child is prone to tantrums or other self-injurious behaviors. Helpful links:

- <http://www.autism-society.org/living-with-autism/how-the-autism-society-can-help/safe-and-sound/safety-in-the-home/>
- <http://www.autismspeaks.org/family-services/resource-library/safety-products>

Read more about safety on pages 47 - 54

Adapted from Smith, M., Segal, J., Hutman, T (2013). *Helping children with Autism Spectrum Disorder: Autism Spectrum Disorder treatment strategies and parenting tips*. Retrieved from <http://www.helpguide.org/mental/autismhelp.htm>.

Step Seven:

Plan for Intervention

Every child with ASD is unique and no one treatment plan will work with every child.

Create a Personalized Intervention Plan

With so many different intervention options available, it can be tough to figure out which approach is right for your child. Making things more complicated, you may hear different or even conflicting recommendations from professionals and from other families. When putting together an intervention plan for your child, keep in mind that there is no single treatment that will work for every individual with ASD. Each person is unique, with different strengths and challenges.

Your child's intervention plan should be tailored to his/her individual needs. You know your child best, so make sure you are communicating his/her needs and advocate to ensure they are met. One way to do that is to ask yourself the following questions:

What are my child's strengths?

What are my child's weaknesses?

What behaviors are causing the most problems?

What important skills does my child lack?

How does my child learn best?

What does my child enjoy and how can those activities be used in his intervention plan?

A good intervention plan will do the following:

- Build on your child's interests
- Offer a predictable schedule
- Teach tasks as a series of simple steps
- Actively engage your child's attention in highly structured activities
- Provide regular reinforcement of behavior
- Involve the family

Finally, keep in mind that no matter what ASD intervention plan is chosen, your involvement is vital to success. You can help your child get the most out of intervention by working hand-in-hand with the team of professionals and following through with the intervention activities at home.

Adapted from Smith, M., Segal, J., Hutman, T (2013). *Helping children with Autism Spectrum Disorder: Autism Spectrum Disorder treatment strategies and parenting tips*. Retrieved from http://www.helpguide.org/mental/autism_help.htm.

Team Approach

Preparing a child with Autism Spectrum Disorder to live a satisfying, happy and productive life is tremendously challenging but incredibly rewarding. As countless families who have made this journey can attest, success requires a committed team that includes not only vigilant and loving family members but also therapists, educators and a host of other professionals and members of the community. Along the way, home based interventions, school services, community outings and social skills groups all have an important role to play.

A team approach to intervention offers the best outcome for a child with ASD. A team may include differing members but should be based on the individualized needs of your child. Each member of the team brings a unique perspective and set of observations and skills, all of which are helpful in assisting your child with complex and variable needs.

You are an equal member of the team. You can offer a valuable and longitudinal view, contributing information and a history of successful (and unsuccessful) strategies. You will also benefit from information on strategies and successes at school that can help to extend learning into the home and community settings. A positive and collaborative relationship is beneficial to everyone.

Your child's team might include:

- a primary care physician who prescribes medication;
- an educator to help you learn to teach your child how to learn;
- an occupational therapist to help with activities of daily living;
- a physical therapist to assist with motor skill development; and
- a speech language pathologist to assist with communication and language skill development;
- a behavioral analyst to assist in understanding challenging behavior and ways to support development of positive social emotional skills; and,
- others based on the needs of the child.

Many children with ASD require various treatments to address all of their symptoms and needs. Common ASD therapy includes:

- Behavior Therapy - www.autismspeaks.org
- Speech-Language Therapy - www.healingthresholds.com
- Play-based Therapy - www.autismspeaks.org
- Physical Therapy - www.cincinnatichildrens.org/services/ot-pt
- Occupational Therapy - <http://www.cincinnatichildrens.org/service/k/autism/default/>
- Nutritional Therapy - <https://www.nichd.nih.gov/health/topics/autism/conditioninfo/Pages/nutritional-therapy.aspx>
- You can also review information on treatments and therapies at www.autismspeaks.org

Step Eight:

Think Inclusion

Inclusion is part of a much larger picture than just placement in the regular class within school. It is being included in life and participating using one's abilities in day to day activities as a member of the community. Inclusion is being a part of what everyone else is, and being welcomed and embraced as a member who belongs.

Inclusion is about all of us

Inclusion is about living full lives – about learning how to live together

Inclusion makes the world our classroom for a full life

Inclusion treasures diversity and builds community

Inclusion is about our 'abilities' – our gifts and how to share them

Inclusion is not just a 'disability' issue

What is Inclusion?

In 1955 the story of a brave and tired woman named Rosa Parks was put in front of this country's awareness. They say this woman had gotten tired, in fact, historically tired of being denied equality. She wanted to be included in society in a full way, something which was denied people labeled as "black" people! So Rosa Parks sat down on a bus in a section reserved for "white" people. When Rosa was told to go to "her place" at the back of the bus, she refused to move, was arrested, and history was challenged and changed. All of this happened because Rosa Parks was tired, historically tired of being excluded. She had sat down and thereby stood up for inclusion!

Another powerful cry for "inclusion" is being heard today. This new cry is being raised by people with unrecognized abilities, (the so-called "disabled"). Many people whose abilities are regularly denied or ignored feel that society is not honoring the right to participate in society in a full way. Part of the call is for better accessibility, such as more wheelchair ramps, more signs and materials in braille, community living, etc. The Americans with Disabilities Act represents an attempt to hear the "inclusion" cry. However, much more needs to be done including a search for an acceptable definition and practice of inclusion.

Across this country a definition of inclusion is offered. It is generally accepted that "Inclusion" means inviting those who have been historically locked out to "come in". This well-intentioned meaning must be strengthened. A weakness of this definition is evident. Who has the authority or right to "invite" others in? And how did the "inviters" get in? Finally, who is doing the excluding? It is time we both recognize and accept that we are all born "in"! No one has the right to invite others in! It definitely becomes our responsibility as a society to remove all barriers which uphold exclusion since none of us have the authority to "invite" others "in"!

So what is inclusion? Inclusion is recognizing our universal "oneness" and interdependence. Inclusion is recognizing that we are "one" even though we are not the "same". The act of inclusion means fighting against exclusion and all of the social diseases exclusion gives birth to - i.e. racism, sexism, handicapism, etc. Fighting for inclusion also involves assuring that all support systems are available to those who need such support. Providing and maintaining a support system is a civic responsibility, not a favor. We were all born "in". Society will immediately improve at the point we honor this truth!!

Ashante, S. (1995). *What is inclusion*. Retrieved from <http://www.inclusion.com/inclusion.html>.

Inclusion in Schools

Inclusion is an educational approach for teaching children with disabilities, such as students with Autism Spectrum Disorder, in the general education classroom. Depending on the needs of the individual student, there could be a special educator or aide added to the general education environment; or, there could be accommodations, modifications, and related services provided by the general educator. Federal mandates such as the Individuals with Disabilities Education Act (IDEA) of 2004 support the inclusion of students with disabilities in general education classrooms. As a result of the inclusion movement, "over the last 15 years or so, there has been a significant increase in the percentage of students with disabilities who receive their instruction in general education classes" (O'Connor, 2016). According to the U.S. Department of Education (2014), about 62% of students with disabilities spend at least 80% of their school day in the general education setting.

There are several benefits to children whose least restrictive environment (LRE) is the general education setting. An environment that is least restrictive, according to *WV Policy 2419: Regulations for the Education of Students with Exceptionalities*, is "one that enables the student to receive IEP services and make reasonable gains toward goals identified in an IEP." Benefits for students with exceptionalities include: enhanced friendships, improved social skills, and more exposure to content. Students with

disabilities are not the only ones who benefit in an inclusive setting. Students without disabilities are exposed to different types of learners and have opportunities to assist others. General educators also have the opportunity to learn about different exceptionalities and add new instructional strategies to their toolkit.

When considering inclusion for a student, the IEP Team should place emphasis on the individual needs of the student and encourage parental input. It is very important to the child's education that members of the IEP team (parent, teachers, principal, etc.) form a solid relationship, keep lines of communication open, and work together as a team to help the child academically, socially, behaviorally, and linguistically. Issues or concerns that arise should be addressed without delay to prevent larger issues. While inclusion is a common approach, it is not the only educational approach in teaching students receiving special education services.

Even with consultation from specialists, a regular school setting cannot always provide the intensive, focused, constant instruction children with autism require throughout the school day. "General education teachers often do not have the training and experience needed to meet the needs of these students" (Leach, 2010). Although schools may have a mandate to educate students who are receiving special education services with age-appropriate, non-exceptional peers to the maximum extent appropriate based on the IEP, the general education setting may not always be the child's least restrictive environment. According to *WV Policy 2419: Regulations for the Education of Students with Exceptionalities*, "removal from the general education environment occurs only when the nature or severity of the exceptionality is such that education in general classes and other settings with general education students cannot be achieved satisfactorily even with the use of supplementary aids and services." In this instance, a child's least restrictive environment may be a separate classroom that serves only special education students. Remember, placements decisions made by the IEP Team should be based on the student's unique needs that result from his or her disability, not on the category of the exceptionality or availability of placement options, services, staff, or space as explained in Ch. 5, Sec. J of WV Policy 2419.

References:

- Leach, D. (2010). *Bringing ABA into your inclusive classroom: a guide to improving outcomes for students with Autism Spectrum Disorders*. Baltimore, MD: Eurospan.
- O'Connor, J. L. (2016). *Great Instruction Great Achievement for Students with Disabilities*. Warner Robins, GA: Council of Administrators of Special Education.
- WV Policy 2419: Regulations for the Education of Students with Exceptionalities. Retrieved from <http://apps.sos.wv.gov/adlaw/csr/readfile.aspx?DocId=26168&Format=PDF>
- <https://medicine.hsc.wvu.edu/pediatrics/faculty-staff/neurology/klingsberg-center/>

Some other things to consider for the inclusive classroom:

- Inclusive Schooling - <http://www.paulakluth.com/readings/inclusive-schooling/>
- Getting Comfortable in the Inclusive Classroom - http://www.paulakluth.com/readings/autism_/getting-comfortable-in-the-inclusive-classroom/

Step Nine:

Find Help and Support

Parents can share information, get advice, and receive support from other parents. Just being around other parents sharing experiences can be helpful and reduce the isolation you may feel.

Find Help and Support

Caring for a child with an ASD can demand a lot of energy and time. There may be days when you feel overwhelmed, stressed, or discouraged. Parenting isn't ever easy, and raising a child with special needs is even more challenging. In order to be the best parent you can be it's essential that you take care of yourself.

Don't try to do everything on your own. You don't have to! There are many places that families of children with ASD can turn to for advice, a helping hand, advocacy, and support:

- **ASD support groups** – Joining an ASD support group is a great way to meet other families dealing with the same challenges you are. Parents can share information, get advice, and lean on each other for emotional support. Just being around others in the same boat and sharing their experience can go a long way toward reducing the isolation many parents feel after receiving a child's ASD diagnosis.
 - Autism Spectrum Disorder Society / National Resources and Support for families - www.autism-society.org
 - Autism Spectrum Disorder Society of WV / State Society of support for families – <http://autismwv.blogspot.com>
 - See the Resources Section of this guide for local ASD support chapters
- **Respite care** – Every parent needs a break now and again. And for parents coping with the added stress of ASD, this is especially true. In respite care, another caregiver takes over temporarily, giving you a break for a few hours, days, or even weeks. Respite can be provided through the I/DD Waiver program/targeted case management/private pay.
- **Individual, marital, or family counseling** – If stress, anxiety, or depression is getting to you, you may want to see a therapist of your own. Therapy is a safe place where you can talk honestly about everything you're feeling or thinking—the good, the bad, and the ugly. Marriage or family therapy can also help you work out problems that the challenges of life with a child with autism are causing in your spousal relationship or with other family members.

Adapted from Smith, M., Segal, J., Hutman, T (2013). *Helping children with Autism Spectrum Disorder: Autism Spectrum Disorder treatment strategies and parenting tips*. Retrieved from http://www.helpguide.org/mental/autism_help.htm.

Know Your Rights

Knowing your rights can help you to feel more in control. Your infant or toddler has a right to appropriate early intervention services if they are eligible for WV Birth to Three supports. Your preschooler to adult child has the right to a free and appropriate public school education. Getting involved in his or her education is among the most important things you can do as your child's advocate. As you'll see below, you have a right to be a part of every decision regarding your child's education, including the process of finding out if your child needs special services. You know your child best, and your input should be considered at every opportunity.

In order to make sure that your child gets the help he or she needs throughout his or her school career, you should familiarize yourself with the rights you have as your child's advocate. These rights are federally mandated by the Individuals with Disabilities Education Act (IDEA).

A list of rights, considerations, and resources follows:

Your Child's Rights Determining Eligibility for Special Education and Related Services

- You have the right to request in writing that your child be evaluated to determine if he or she is eligible for special education and related services. This evaluation is more than just a single test. The school must gather information from you, your child's teacher, and others who would be helpful. An assessment of your child must then be conducted in all the areas that may be affected by the suspected disability.
- If the public school agrees that your child may have a learning disability and may need special help, the school must evaluate your child at no cost to you.
- Teachers or other professionals can recommend that your child be evaluated, but the school must get your explicit written consent before any part of the evaluation is started.
- If the public school system refuses to give your child an evaluation, they must explain in writing the reasons for refusal, and must also provide information about how you can challenge their decision.
- All tests and interviews must be conducted in your child's native language. The evaluation process cannot discriminate against your child because he or she is not a native English speaker, has a disability, or is from a different racial or cultural background.
- Your child cannot be determined eligible for special education services only because of limited English proficiency or because of lack of instruction in reading or math.
- You have the right to be a part of the evaluation team that decides what information is needed to determine whether your child is eligible.
- You have the right to a copy of all evaluation reports and paperwork related to your child.
- You have the right to obtain an Independent Education Evaluation from a qualified professional and challenge the findings of the school evaluation team.
- You have the right for your child's evaluation to be completed within a specific timeframe. Some states have set a limit. For states who had no limit, as of July 1, 2005, the evaluation must be completed within 60 days of your written consent.

Your Child's Rights Once Determined Eligible for Special Education and Related Services

- You and your child have the right to attend and participate in a meeting to design an Individualized Education Program (IEP) which must be held within 30 days of your child being found eligible for special education services. An IEP should set reasonable learning goals for your child and state the services that the school district will provide.
- You and your child have the right to participate in the development of the IEP, along with a team that will include: your child's teachers, a representative from the school administration who is qualified to recommend and supervise special programs and services as well as representatives from other agencies that may be involved in your child's transition services (if your child is age 16 or older). You can also request an advisor to help you better understand your rights and responsibilities as a parent, and request that this person be present.
- Your child has a right to the least restrictive environment possible. Unless members of the IEP team can justify removal from the general education classroom, your child should receive instruction and support with classmates that do not have disabilities. Also be sure that special education services or supports are available to help your child participate in extracurricular activities such as clubs and sports.
- During an IEP meeting, the IEP team will develop goals for any related services, such as occupational therapy, which could help your child. Be sure the team specifies how often and for how long these services will be provided as well as in what setting the services will be provided. This team will also identify behavioral strategies to support your child's learning in school and at home.
- Be sure to discuss what kind of assistive technology devices such as: speech recognition software, speech-to-text or text-to-speech apps and programs, electronic organizers, digital books, Picture Exchange Communication System (PECS), and communication apps/software/devices.
- You have the right to challenge the school's decisions concerning your child. If you disagree with a decision that's been made, discuss it with the school and see if an agreement can be reached. If all efforts don't work, IDEA provides other means of protection for parents and children under the law. These other ways of settling your dispute allow parents and school personnel to resolve disagreements. Options include mediation with an impartial third person, a due process hearing, or a formal hearing in a court of law.

- An IEP meeting must be held once a year and comprehensive re-evaluation must be done every three years, unless the IEP team agrees that it is not necessary. However, you may request an IEP meeting at any time.

Helpful links:

- WV Birth to Three
 - Information for families – <http://www.wvdhhr.org/birth23/families.asp>
 - Procedural Safeguards - <http://www.wvdhhr.org/birth23/families.asp>
- WV Department of Education
 - Policy 2419 – <http://apps.sos.wv.gov/adlaw/csr/readfile.aspx?DocId=26168&Format=PDF>
 - Hand in Hand in Special Education - <http://wvde.state.wv.us/osp/handinhand.pdf>
 - Parent Educator Resource Centers - <http://wvde.state.wv.us/osp/perc.html>
- Building Partnerships Between Families, Schools and Communities - <http://www.bridges4kids.org/>
- Special Education website - <http://www.wrightslaw.com/>

Adapted from the National Center on Learning Disabilities Editorial Team (n.d.). *Knowing your child's rights*. Retrieved from <https://www.nclد.org/wp-content/uploads/2014/11/IDEA-Parent-Guide1.pdf>

Step Ten:

Think About Challenges in a New Way!

There may be times that you cannot come up with a solution. What to do? Think in a different way!

How to Think 'Outside the Box'

Throughout this publication we have discussed the importance of consistency and routine for individuals with ASD. However, you might find yourself in a situation where the routine ways you have addressed questions or challenges simply is not helping you to find a solution that is really effective. Maybe you have also considered or used one or more of the following:

- Write about the problem
- Back off and do nothing
- Consult with someone new
- Observe, is your child showing you a solution through his behavior?
- Take time to re-direct, ask your child's doctor, teacher, therapist for assistance

If you have still you have not found something to work. Well, that's when it's time to step outside of the box.

No doubt you have heard the term to 'think outside the box'. Perhaps you have wondered what that meant in actual fact, or maybe you know what it means but you're so firmly "inside the box" that you don't even notice that you're in the box. We always need to be on the lookout for new ideas and it's the ability to think differently, generate new ideas, and spark your creativity. You do need to actively work on building and cultivating these skills – but it can be done!

Generate New Ideas

Standard idea-generation techniques concentrate on combining or adapting existing ideas. This can certainly generate results. But our focus is on equipping you with tools that help you leap onto a totally different plane. These approaches push your mind to forge new connections, think differently, and consider new perspectives.

While these techniques are extremely effective, they will only succeed if they are backed by rich knowledge of the area on which you're working. This is where all the knowledge you have gained about ASD, as well as the professional and family connections you've made come into play.

Breaking Through Patterns

All of us can tend to get stuck in certain thinking patterns. Breaking these thought patterns can help you get your mind unstuck and generate new ideas. There are several techniques you can use to break established thought patterns:

- **Challenge assumptions:** For every situation, you have a set of key assumptions. Challenging these assumptions gives you a whole new spin on possibilities.
- **Reword the problem:** Stating the problem differently often leads to different ideas. To reword the problem look at the issue from different angles. "Why do we need to solve the problem?", "What's the roadblock here?", "What will happen if we don't solve the problem?" These questions will give you new insights. You might come up with new ideas to solve your new problem.
- **Think in reverse:** If you feel you cannot think of anything new, try turning things upside-down. Instead of focusing on how you could solve a problem, consider how you could create the problem. The reverse ideas will come flowing in. Consider these ideas – once you've reversed them again – as possible solutions for the original challenge.
- **Express yourself through different media:** How about expressing the challenge through different media? Clay, music, word association games, and paint there are several ways you can express the challenge. Don't bother about solving the challenge at this point - just express it. Different expressions might spark off different thought patterns and yield new ideas.

Connect the Unconnected

Some of the best ideas seem to occur just by chance. You see something or you hear someone, often totally unconnected to the situation you are trying to resolve, and the penny drops in place. Why does this happen? The random element provides a new stimulus and gets our brain cells ticking. You can capitalize on this knowledge by consciously trying to connect the unconnected.

Actively seek stimuli from unexpected places and then see if you can use these stimuli to build a connection with your situation. Some techniques you could use are:

- **Mind map possible ideas:** Put a key word or phrase in the middle of the page. Write whatever else comes in your mind on the same page. See if you can make any connections.
- **Pick up a picture.** Consider how you can relate it to your situation.
- **Take an item.** Ask yourself questions such as "How could this item help in addressing the challenge?", or "What attributes of this item could help us solve our challenge?"

Shift Perspective

Over the years we all build a certain type of perspective and this perspective yields a certain type of idea. If you want different ideas, you will have to shift your perspective. To do so:

- **Get someone else's perspective:** Ask different people what they would do if faced with your challenge. You could approach friends engaged in different kind of work, your spouse, a nine-year old child, customers, suppliers, senior citizens, or someone from a different culture; in essence anyone who might see things differently.
- **Play the "If I were" game:** Ask yourself "If I were ..." how would I address this challenge? You could be anyone: a millionaire, Tiger Woods, anyone. The idea is the person you decide to be has certain identifiable traits, and perfection, and you have to use these traits to address the challenge. For instance, if you decide to play the millionaire, you might want to bring traits such as flamboyance, big thinking, and risk-taking when formulating an idea. If you are Tiger Woods, you would focus on things such as perfection, persistence, and execution detail.

Employ Enablers

Enablers are activities and actions that assist with, rather than directly provoke, idea generation. They create a positive atmosphere. Some of the enablers that can help you get your creative juices flowing are:

- **Belief in yourself:** Believe that you are creative, and believe that ideas will come to you; positive reinforcement helps you perform better.
- **Creative loafing time:** Nap, go for a walk, listen to music, play with your child, or take a break from formal idea-generating. Your mind needs the rest and will often come up with connections precisely when it isn't trying to make them.
- **Change of environment:** Sometimes, changing the setting changes your thought process. Go to a nearby coffee shop instead of the conference room in your office, or hold your discussion while walking together round a local park.
- **Shutting out distractions:** Keep your thinking space both literally and mentally clutter-free. Put away the phone, divert your phone calls, close the door, and then, think.
- **Fun and humor:** These are essential ingredients, especially in team settings.

Final Thoughts

The ability to generate new ideas is an essential skill. You can acquire this skill by consciously practicing techniques that force your mind to forge new connections, break old thought patterns, and consider new perspectives. Along with practicing these techniques, you need to adopt enabling strategies, too. These enabling strategies help in creating a positive atmosphere that boosts creativity.

- Be willing to explore things that are out of your comfort zone. It's refreshing, and you can find new interests and meet new people.
- Read biographies to see how other people overcame ruts in their lives. Adapt their thinking solutions to your current situation.
- Read something that isn't your usual genre. For example, if you think you *hate* crime fiction, why not try reading one? You might be pleasantly surprised; even if not, you've challenged your thinking processes. Be sure to read to the end!
- Explore faiths beyond your own. Try to find the similarities and connections, and aim to accept

each for what it is.

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Mediawiki, (2013). *How to think outside of the box*. Retrieved from <http://www.wikihow.com/Think-'Outside-of-the-Box'>.

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Next Steps Checklist

Complete	#	Action																																	
	1	Call the WV Birth to Three Regional Coordinator or County Special Education Director: Name: _____ Phone _____ _____ Items for discussion: A: _____ B: _____ C: _____																																	
	2	Organize your documents A. Begin a binder to store documentation – you may contact the Parent Network Specialists with the Center for Excellence in Disabilities for assistance with this (see page 61). B. Make copies of documents to share with others – never give away your originals. C. Documents to have on hand: <ul style="list-style-type: none"> • Social Security Card/Number • WV Department of Vital Statistics Birth Certificate • Diagnostic paperwork • Pertinent medical work • Immunization records 																																	
	3	Investigate services for which you and your child may be eligible <table border="1" style="width: 100%; border-collapse: collapse; margin-top: 5px;"> <thead> <tr> <th style="width: 33%;">Service</th> <th style="width: 33%;">Contact Person</th> <th style="width: 34%;">Contact Information</th> </tr> </thead> <tbody> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> </tbody> </table>	Service	Contact Person	Contact Information																														
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	4	Access the WV Team Autism Website - https://sites.google.com/site/wvteamautism/																																	
	5	Call your regional contact person to review roadblocks and successes of steps 1-4. <table border="1" style="width: 100%; border-collapse: collapse; margin-top: 5px;"> <tbody> <tr> <td style="width: 60%;">WV Birth to Three</td> <td>See page 58</td> </tr> <tr> <td>County Special Education Director</td> <td>See page 59</td> </tr> <tr> <td>Parent Educator Resource Center</td> <td>See page 59</td> </tr> <tr><td> </td><td> </td></tr> <tr><td> </td><td> </td></tr> <tr><td> </td><td> </td></tr> </tbody> </table>	WV Birth to Three	See page 58	County Special Education Director	See page 59	Parent Educator Resource Center	See page 59																											
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Step Eleven:

Getting Organized

Organizing and keeping paperwork will provide you an opportunity to maintain all the information you have learned about Autism Spectrum Disorder, along with the educational records, medical records, and information from other agencies in one place. This will make it easier for you to locate information when you need it!

Organizing Your Child's Special Education File: Do It Right!

The special education system generates mountains of paper. Some information is important so you are afraid to throw anything away. The mountain of paper grows higher every year. What do you do with it? How do you organize this information?

You need a simple, foolproof document management system. In this article, you will learn how to organize your child's file. After you organize the information about your child into a file, you will have a clearer understanding of your child's disability and needs.

Document Management Systems

Think about the last school meeting. Did the IEP team members have a complete copy of your child's file? Did you have a complete copy of your child's file? How can the IEP team make decisions about your child's special education program if they do not have complete, accurate information about your child? Schools keep records in different places. Information and reports are misplaced. When you organize your child's file, you will have all the information about your child in one place. With our document management system, you can track your child's educational history. When you use this parent-tested system, you can quickly locate any document in your child's file.

When you take your organized file to the next school meeting, you will understand the power of getting organized. You will gain a sense of control.

Gather Information about Your Child

Follow these steps to get information about your child.

1. *Make a Master Provider List*

Make a list of all individuals and agencies that may have information or records about your child. Your list should include the names and titles of all professionals who have provided medical or mental health treatment services, including doctors, therapists, and other health care providers. Include their addresses, telephone and fax numbers, and email addresses. You may want to develop your list by category of service rendered, e.g., medical, educational, psychological evaluations. **Master Provider List** - <http://www.wrightslaw.com>

2. *Request Your Child's Records*

Send a letter to all individuals and agencies on your list and request a copy of your child's records. Explain that your request relates to a school issue and the need to secure an appropriate education for your child. Ask if you should expect to pay a photocopying fee and what this fee will be. Your letters should be neat and convey a professional image.

- **Tip:** See Chapter 23 in [Wrightslaw: From Emotions to Advocacy](http://www.wrightslaw.com) (<http://www.wrightslaw.com>) for sample letters to request information and records - If you do not receive a response within ten days, send a short letter explaining that you requested information ten days ago and have not received a response. Attach a copy of your original letter to the second request letter. Ask if you can do anything to help expedite the request. Offer to visit the office to help copy the information. Be polite.
- **Tip:** Make photocopies of all letters for your file.

3. *Request Your Child's Educational Records*

Write a letter to the school and request a complete copy of your child's entire cumulative file and confidential file, omitting nothing. You want copies of all evaluations, records, correspondence, and other documents the school has about your child. Use a word processor for your letter. Expect to pay a reasonable photocopying fee.

- **Tip:** See more sample letters at the end of Chapters 23 and 24 in *Wrightslaw: From Emotions to Advocacy*. - <http://www.wrightslaw.com/store/feta.html>
- Send one letter to the principal of your child's school and one letter to the director of special education. If you do not know the director's name and address, call the main office of the school district and request this information. If your child does not attend a public school, send the letter to the principal of the last public school your child attended.
- Before you mail these letters, sign them and make copies of the signed letters for your Master File. Log the letters into your contact log.

4. Organize the Master File

You will organize and file all information about your child in a large binder. Gather all documents that relate to your child. Bring all paper in boxes, file folders, and bags together in one place. Begin by organizing the documents by year.

Step 1: Date All Documents

- With a pencil, lightly write the date of each document in the lower right corner of the first page (Example: 05/09/12).
- **Tip:** Use a soft lead pencil when you date the documents. You may need to erase your notations later.
- Before long, mail will roll in from your requests. Using a pencil, lightly date each document in the lower right hand corner. Date everything- evaluations, reports, correspondence, report cards, and medical reports.
- When you find duplicate documents, compare the duplicates, decide which document has the best photocopy quality, and use this as your master. Put the duplicates in a box. You will not need them for your notebook. Do not throw them away. You may need to provide copies to other people later.
- **Tip:** Do not write on original documents. You may need these documents later.
- *Do not stop to read the documents.* Many parents say that when they organize documents, they begin to read and are sidetracked. Force yourself to stick with this job until you finish. Just date and organize! Lightly pencil the date on the bottom right corner of the first page.
- **Tip:** Work samples provide useful information about your child's skills. Include a few samples of your child's schoolwork.

Step 2: File All Documents in a large Binder

- File all dated documents in a large binder. Sometimes you might have two or three binders. When documents are formatted horizontally, date and place them in a portrait vertical style.
- File all documents in chronological order, oldest document on top and newest document at the end. Some parents use the child's birth certificate as the first document in the file. The last document is the most recent piece of information. This may be a report card, IEP, or letter from the school.
- **Tip:** Do not put documents in clear plastic envelopes. If you are in a meeting and need to find a document in the file, removing documents from plastic envelopes takes too long.
- Do not file documents by category (i.e., IEPs, psychological evaluations, correspondence, etc.). If you file documents by category, your system will fail. Assume you have a comprehensive letter written by a child psychologist three years ago. The Eligibility Committee and the IEP team used the psychologist's letter. Is this document a letter? A report? An evaluation?
- *If your system is confusing and difficult, it will fail.* Trying to figure out categories is confusing and time-consuming. Use our parent-tested system. You have better things to do with your time!

Step 3: Read the Master File for the "Big Picture"

- After you complete Step 2, read your child's Master File from beginning to end. When you read the information chronologically, you will see the big picture.
- At the beginning of this article, I mentioned the mountains of paper generated by the special education system. After reports are written, they are filed away. Few people will read or review this information again.
- Because there is no master plan, no one looks at the big picture.
- Instead of looking at the forest, parents and school staff focus on the bark of the trees. When you organize your child's file, you will see the forest. You will understand. Many parents say that making a neat, organized, chronological Master File is a powerful educational experience.

Create Your Document List

You have dated the documents and filed them in chronological order, oldest document on top, most recent on the bottom. Now you need to create your Master Document List. When you

organize documents chronologically and generate your Master Document List, you can compress your child's history into a few pages. You can locate any document in seconds.

To create your Master Document List, make a table with four columns. If you are using a word processing program, insert a four-column table.

- **Tip:** If you use a word processing program, the program can sort the list by date, author, or type of document. If you are not using a computer, draw a table with four columns on several sheets of paper.
- Label the columns: Date, Author, Type, and Significance.
- Enter each document by date, author, and type. You can leave the "Significance" column blank for now. When you use a word processing program, you can change the font to highlight test data and other important information. This makes it easier to find important information.
- **Tip:** When you use a word processing program, you can change the font to highlight test data and other important information. You make it easier to find important information. For a sample document list - <http://www.fetaweb.com>
- **Tip:** If you want to make a note on a document in your Master File, write on a sticky note that you attach to the document.
- Attach sticky notes to all pages in your Master File that have test scores (i.e., the Wechsler Intelligence Test and Woodcock Johnson Tests.) Sample master documentation list - <http://www.fetaweb.com>
- When you organize your child's file, you will learn about your child's disability and educational history. This is an important step in becoming an expert. When you finish this job, you will have a clearer understanding of your child's educational needs.
- You do not need to complete the "Significance" column yet. When you learn more about evaluations and test scores, you will recognize important information in documents.
- **Tip:** See how a Master Document List is used to create an Exhibit List (sample - <http://www.fetaweb.com> for a due process hearing.
- As you organize your child's file, you will learn about your child's disability and educational history. You will have a clearer understanding of your child's academic and functional needs. After you create your Master Document List, you will be able to find a specific document quickly and easily. These are important steps in becoming an effective advocate for your child.

More Articles about Documents and Organizing Information

- **The Paper Chase: Managing Your Child's Documents Under the IDEA** by Bob Crabtree, Esq. If you have kids with special educational needs, you can be overwhelmed by paperwork in no time. This article teaches you about the importance of different documents and how to organize them. You learn about documents that are keepers; education records; documents you should create and how; tips for consulting with an attorney. - <http://www.fetaweb.com/03/paperchase.crabtree.htm>
- **Paper Trails: Documents, Exhibit Lists and Due Process Hearings** by Pete Wright. This is one of several articles about documents that was published in the - <http://www.harborouselaw.com/articles/docs.prepare.wright.htm>
- **Paper Trails, Letter Writing and Documentation.** When you advocate for a child, you use logs, calendars, and journals to create paper trails. - <http://www.wrightslaw.com/info/ltrs.index.htm>

For assistance in developing an organization or record keeping system, see the Center for Excellence in Disabilities – Parent Network Specialists on page 61.

Adapted from Wright, P. (2013). *Organizing your child's special education file: Do it right*. Retrieved from <http://www.wrightslaw.com/info/organize.file.htm>.

HELPFUL INFORMATION FOR CRISIS AND EMERGENCIES

Remember, in an Emergency –
it is
“Emergency First, Autism Spectrum Disorder Second”

Emergencies, Crisis and Safety

When a Crisis or Emergency Arises

All families sometimes experience a crisis with their child. Whether it is a medical emergency, a behavioral challenge or when a child wanders away, times of crisis are stressful. For families of children with ASD, a crisis can be particularly challenging. Many individuals with ASD have aversions to doctors and medical procedures. They may have difficulty regulating their behavior so that emergency personnel can intervene appropriately. What is most important is to be prepared in the event of a medical, behavioral or wandering away crisis. Here are some tips to assist you to prepare.

Preparation

- ▶ Keep the phone number of your physician, your local hospital and an ambulance service near your phone or in an area where it can be quickly accessed.
- ▶ Think about who might assist you in the event of an emergency or crisis. It could be an extended family member, a neighbor or a friend. It should be someone familiar with the individual. Talk to them about the fact you might sometime need some support and direct assistance in the event of an emergency.

Ask if they would be willing to help. Keep the phone numbers of those people near the phone or in an area for quick access.

- ▶ If the individual has a history of exhibiting serious challenging behavior, have a step by plan on how you will react. Seek the assistance of the individual's teacher, a behavior analyst, psychologist, or behavioral specialist in designing the plan. Post the plan in an easy to access place. Review the plan with all family members and anyone who has offered to assist you.
- ▶ Develop a medical/behavioral emergency information sheet. The sheet should list
 - The *diagnosis* of the individual
 - Any *additional known medical problems* such as allergies or other medical conditions
 - All *medications and dosages*
 - All *medications that have NOT worked* in the past
 - Information about the *individual's behavioral profile*. For example, "Joey is sensitive to other people's touch and bright lights. Loud noises frighten him. Directions must be given in a clear and concise manner. While he has limited speech, he will understand most of what you saying to him. He needs to know what is happening now and what will happen next."

Make multiple copies of the information sheet and hand it to anyone involved in the individuals care during the emergency (i.e. ambulance staff, waiting room assistants, nurses and doctors). Make sure they understand the information on the sheet is important and critical to the care of the individual. It is also a good idea to keep multiple copies of the information sheet in the glove compartment of your car.

A sample form provided by AUTISM Emergency Medical Services (AUTISM EMS) is included in this section.

In summary: from the AUTISM PREPARIDNESS FOR EMS PROFESSIONALS WEBSITE www.autismems.net. (This can be used as a checklist).

- **STEP ONE: PREPARE A PSYCHOLOGICAL PLAN:**

Write down, in notebook things you could do if an emergency occurs. Have a list of emergency

numbers, health care providers, family and friends you can call if an emergency arises.

- **STEP TWO: PREPARE A BEHAVIORAL PLAN**

If your child has a meltdown that escalates, do you have a backup plan to address aggressive behavior?

- **STEP THREE: PREPARE AN EMERGENCY PLAN**

Have a plan that clearly outlines steps to give caregivers and professionals should take if the situation escalates. This plan may consist of specific behavioral intervention/medications used or treatment options

During an Emergency or Crisis

When an emergency or crisis arises, the most important thing you can do is to stay calm. A simple strategy to assist you to stay as calm as possible is to take deep breaths. If you have taken the steps above, you ARE prepared to handle the problem. Assure yourself of this. Do not hesitate to call for immediate assistance from those who have offered to help.

MORE INFORMATION ON EMERGENCY PREPAREDNESS ESSENTIAL FOR PERSONS WITH AUTISM SPECTRUM DISORDER/SIX ACTIONS TO PREPARE FOR AN EMERGENCY SITUATION

To review this emergency plan go to: <http://www.ausm.org/emergency-preparedness/98-family-emergency-essentials-kit.html>

- Action One: Assess Your Risk
- Action Two: Identify Yourself
- Action Three: Educate Your Support Network
- Action Four: Make a Plan and Practice
- Action Five: As needed, prepare for wandering
- Action Six: Be an Advocate

You might want to explore the autism five point scale emergency app. The download has a voice activated system that for each level of stress will speak for the individual:



You will find a link to iTunes on the above listed link. You can also find the App in the Google Play Store at <https://play.google.com/store/apps/details?id=air.autism5pointandroid11&hl=en>

AUTISM EMERGENCY KIT

Who is providing this kit?

Autism EMS is a website and web resource designed for EMS professionals and dedicated to improving the relationship between EMS providers and those who are affected by an ASD. Although, EMS is not currently using this document you should complete it in case of an emergency to give to medical or emergency personnel as a way to describe your child's needs. The website also collects information from persons with Autism Spectrum Disorder and/or their family members or caregivers on experiences with EMS providers. If you have had such an experience, please visit <http://autismems.net/> to tell us about it!

What the kit includes:

The Autism Emergency Information Kit includes several forms that will be useful if your loved one with ASD becomes ill, is injured or wanders away. These forms include:

- Personal Medical Information (PMI): Basic information about a person's medical history, medications, and allergies, as well as key demographic information that is needed to register in a hospital emergency department.
- Autism Emergency Information (AEI): Specific information about how the person's ASD may affect the ability of a healthcare provider or rescue worker to interact with the person.
- The "Wander Profile": This is a single-sided, one-page form that provides essential information to persons involved in search-and-rescue operations if the person with ASD wanders. The form can be easily photocopied for distribution if needed
- A map form: Grid paper is provided to assist in drawing a map of the area surrounding the home. This map can be accessed by going to <http://www.autismems.net/5101.html>.

Copies of all forms in the ASD Emergency Kit are available free of charge by visiting [http://autismems.net/media/aek\\$20complete.pdf](http://autismems.net/media/aek$20complete.pdf) . Additional information can be obtained by emailing autismems@verizon.net .

*The personal medical information (PMI) form may be duplicated (and distributed) independently of the kit. **The PMI form is appropriate for all persons and may be used for anyone.***

Preparing for Disaster for People with Disabilities and Other Special Needs

For the millions of Americans who have physical, medical, sensory or cognitive disabilities, emergencies such as fires, floods and acts of terrorism present a real challenge. The same challenge also applies to the elderly and other special needs populations. This booklet will help people with disabilities prepare and emergency plan to protect themselves, family, friends, personal care assistant and others in the support network in the event of an emergency. Post the plan where everyone will see it, keep a copy with you and make sure everyone involved in your plan has a copy. Please visit <https://www.fema.gov/media-library/assets/documents/897> for additional information.

EMERGENCY PREPAREDNESS FOR ADULTS WITH ASD

Dennis Debbaudt (2012) - <http://www.autismriskmanagement.com/>

Information about preparing or preventing an emergency

- Securing the home and anti-wandering technology
- Keep records
- Contacting 911 Call Centers
- Autism Emergency Contact Forms
- Considering Autism Icons
- ID Options
- Building Skills for children and less independent adults
- Building Skills for more independent adolescents or adults who has autism or Asperger Syndrome
- Avoiding victimization
 - Individuals with autism may need to take extra precautions in order to avoid detection, arrest, prosecution or avoid becoming a victim. Below are some tips to use.
 - Avoid areas that are unfamiliar to you
 - Consider carrying a cell phone
 - Travel in groups if possible or walk with the crowd
 - Do not dawdle or appear rushed in a crowd
 - Park in a secure area
 - Keep car doors locked
 - Take a look around the parking lot before unlocking your car and exiting your vehicle
 - Arrive with the crowd to work, school or events
 - Avoid staring
 - Do not maintain long eye contact
 - Let someone know when you plan to travel
 - Do not carry or show large amounts of cash or credit card
 - Dress to fit in the area
 - Stay in well-lit areas
 - Do not wander or explore off well-traveled walkways

BE SAFE/The Movie

This video is a good teaching tool in "How to interact with the police". It teaches safety skills using real scenarios and real police to help individuals to know when a police encounter occurs:

1. Stay calm
2. Stay where you are. Do not run
3. Do what the police tell you to do.

You will find the video at <http://www.besafethemovie.com/>.

Information for Finding Crisis Placements in West Virginia

In the event of a serious behavioral crisis additional supports may be needed. West Virginia has several placements for behavioral crisis situations that cannot be remedied through an emergency room or when the backup behavioral plans consistently fail.

HOW TO USE THE FOLLOWING LIST:

1. There are no longer requirements for a centralized intake in a crisis situation. So parents may call their service coordinator, adult protective service guardian or starlight behavioral health services for information
2. Every crisis unit now has a behavioral support professional on staff
3. If the individual is on the I/DD waiver program, contact your service coordinator
4. If the individual is under an adult protective services guardian (non-waiver) contact them
5. Contact starlight behavioral services - they are a great starting point to answer questions about crisis units and have two staff hired to assist with those inquiries. Starlight behavioral services can be reached **at 304-302-2078**

The following resources are available for adults with an intellectual/developmental disability who need Crisis Respite to provide temporary substitute care in a residential setting due to behavioral needs or lack of supports, or Planned Respite to provide periodic planned breaks for the individual and caregiver.

Crisis Respite Resources for Adults with Intellectual /Developmental Disability

Crisis Site	Address & Number's	Contact	Additional Information
REM, Inc. - Keyser <ul style="list-style-type: none"> • Rosemary Wilshire - Reg Dir • Scott Baughman- Program Director/ Area Manager • <u>Laura Cox</u> – Program Coordinator/Resource Coordinator 	Rt 220 S Keyser, WV 26757 304-788-9730 After Hours - Call pager 877-821-0160	Office will direct your call to individual covering crisis bed referrals. rosemary.wilshire@thementornetwork.com scott.baughman@thementornetwork.com Crisis site intake and referral: laura.cox@thementornetwork.com	<ul style="list-style-type: none"> • 3 bed capacity • Rural Setting • 1:1 staffing available • Intensive behavioral evaluation • Intensive nursing services
REM, Inc. - St. Marys <ul style="list-style-type: none"> • Jason Lynch, Regional Director • Ross Mason, Regional Director • Clara Maidens- Program Director • <u>Stacy Sprouse</u>- Program Coordinator 	732 Oak Grove Ext Rd. St. Marys, WV 26170 Pleasants County 304-684-1282 St. Marys Office 304-684-1010 Fax: 304-684-1011 After hours 304-481-1459 Fax: 304-684-1011	St. Mary's Office-They will direct your call to someone covering crisis bed referrals. Jason.lynch@thementornetwork.com Ross.mason@thementornetwork.com Clara.maidens@thementornetwork.com Crisis site intake and referral: stacy.sprouse@thementornetwork.com	<ul style="list-style-type: none"> • Capacity is 3 beds/Co-ed • House in rural setting • 1:1 staffing available • Intensive behavioral evaluation • Intensive nursing services

Crisis Site	Address & Number's	Contact	Additional Information
REM, Inc - Bridgeport <ul style="list-style-type: none"> Rosemary Wilshire, Regional Director Jim Davis- Program Director Sammi Wyant- Program Coordinator <u>Debbie Slick</u>- Resource Coordinator 	408 E. Main St. Bridgeport, WV 26330 Harrison County 304-842-9054 Fax: 304-842-9062	Rosemary.wilshire@thementornetwork.com Jim.davis@thementornetwork.com Sammi.wyant@thementornetwork.com Crisis site intake and referral: Debbie.slick@thementornetowrk.com	<ul style="list-style-type: none"> Capacity is 3 beds/ Co-ed House in rural setting 1:1 staffing available Intensive behavioral evaluation Intensive nursing services
REM, Inc - Beckley <u>Karen Dawson</u>	409 Massey St. Beckley, WV	<i>Coming Soon! They are in the process of opening a site in Beckley, waiting to be licensed as of 1/12/17.</i>	
Southern Highlands <ul style="list-style-type: none"> Michael Lewis- Program Director <u>Jeremey Burks</u> - Program Coordinator/ Resource Coordinator 	329 Mercer St Princeton, WV 24740 304-487-1488 Fax: 487-1512 After Hours – 304- 487-1488 Fax: 487-1512	Carl Pennington, Program Director michaellewis@shcmhc.com Crisis Referral and intake contact: Jeremyburks@shcmhc.com	<ul style="list-style-type: none"> Capacity is 3 beds/Co-ed Apartment setting in downtown Princeton 1:1 staffing available

I/DD Crisis Respite – Children

Crisis Site	Address & Numbers	Contact	Additional Information
Braley & Thompson <u>Andrea Blankinship</u> - Program Director/ Resource Coordinator	1 Dunbar Plaza Dunbar, WV 25064 304-720-2331 x 405 Fax: 304-205-6043 After hours – 681-205-4122 OR 304-382-8768	Jeff Shrewsbury jshrewsbury@rescare.com Crisis Referral and intake contact: Andrea.blankinship@rescare.com	<ul style="list-style-type: none"> 3 bed capacity Rural Setting

ADDITIONAL RESOURCES for PLANNED RESPITE

Short term, planned respite for adults may also be arranged on a case by case basis through the following services

- ICF/IID program.** Contact Pat Nisbet at 304-356-4904 (Patricia.S.Nisbet@wv.gov) or Kelly Johnson at 304-356-4886 (Kelley.S.Johnson@wv.gov)
- Adult Family Care program.** Contact Michelle Saxton at 304-558-7980 (Michelle.C.Saxton@wv.gov)
- Specialized Family Care program.** Contact Teresa McCourt at 304-720-3200 x213 (Teresa.L.McCourt@wv.gov)

Project Lifesaver

From the Project Lifesaver website: Project Lifesaver is the premier Search & Rescue (SAR) program specifically designed for “At Risk” individuals who are prone to the life threatening behavior of wandering. Citizens enrolled in Project Lifesaver wear a small personal transmitter around the wrist or ankle that emits an individualized tracking signal. If an enrolled client goes missing, the caregiver notifies their local Project Lifesaver agency, and a trained emergency team responds to the wanderer’s area. Most who wander are found within a few miles from home, and search times have been reduced from hours and days to minutes. Recovery times for PLI clients average 30 minutes — 95% less time than standard operations. For more information on how Project Lifesaver works, visit their website at <http://www.projectlifesaver.org/>

In North Central West Virginia, The Corridor Chapter provides funding for people with ASD who need a bracelet in the counties of Monongalia, Marion, Harrison, Taylor, Doddridge and Lewis. Peggy Hovatter is the contact person. You can reach her at hovatter@marshall.edu or leave a message at 800-304-344 5115.

If you are not in one of these counties, search equipment may be available through your local police or fire department. You can visit <http://www.projectlifesaver.org/where-we-are/> to check your area to see if it is available and to find contact information for your local agency supporting the program. Initial set up is very expensive and personnel monitoring this service need to be well trained.

Suggestions for Securing Your Home for a Wandering Child Information taken from the National Autism Association:

- Install secure deadbolts locks that require keys on both sides of the door
- Install a home security alarm system
- Install inexpensive battery-operated alarms on doors and windows. These products are available at Radio Shack, Wal-Mart, Home Depot and Lowes or go to the following website: <http://www.mypreciouskid.com>

AUTISM RISK & SAFETY MANAGEMENT - Contact Dennis Debault 772-398-9756 - National Autism Spectrum Disorder risk & safety expert for information. Go to: <http://www.autismriskmanagement.com>

You can download the following files:

- IEP’s
- Autism Spectrum Disorder Emergency Contact Forms
- Building Life Skills
- Autism – Airport and Travel Safety
- Autism and the Risk to Drive
- 25 Autism Spectrum Disorder Tips for Law Enforcement

AMBER ALERT OF WEST VIRGINIA

What is Amber Alert? Amber Alert is a voluntary partnership between the WV State Police, WV Broadcasters, WV Emergency Alert System Committee and the National Weather Service to send out an emergency message to alert the public when a child has been abducted and it is believed the child’s life is in danger.

- Law enforcement confirms a child 17 years of age or younger has been abducted
- Law enforcement believes the circumstances surrounding the abduction indicate that the child is in danger of serious bodily harm or death
- Law enforcement has enough descriptive information about the child, abductor and suspect’s vehicle to broadcast and enter the abducted child into the NCIC to activate the amber alert.

How does Amber Alert work? Once a determination is made that the use of the Emergency Alert System may aid in locating of an abducted child, the WV State Police will provide as much detailed information as reported by the investigating agency. This information will be broadcast over a three-hour period via television and radio. During the first hour, the Amber Alert will be broadcast every fifteen minutes. During the second and third hours, the information will be sent every half hour. In the event that the Amber Alert is cancelled, for whatever reason, the use of the Amber Alert will be immediately discontinued.

For more information contact:
The WV State Police
725 Jefferson Road
South Charleston, WV 25309
304-746-2133

Supporting Safety in the Home

Below, you will find helpful information and suggestions about how to help you prevent accidents and other crisis. There are many websites that provide additional information and we suggest that you explore these as prevention is the key.

Autism Speaks (2013) Provides a guide that reviews safety in the home, which you may find at <https://www.autismspeaks.org/wandering-resources>

Practicing safety skills takes time and encouragement

3 Paths to Safety

1. Use prompts
2. Use positive reinforcement
3. Use role playing
4. Have a safety plan

Other ID Possibilities:

Medic Alert Foundation - The Medic-Alert plus the Safe and Sound program will provide comprehensive services that can safeguard and identify individuals with Autism Spectrum Disorder in an emergency. Each individual enrolled in the program will be provided with a personalized medical ID and wallet card that provides emergency responders with identification information and details on critical medical conditions <http://www.medicalert.org/>

Additional Safety Resources:

Lo Jack SafetyNet - Protection for People Who Wander Away - <http://www.lojack.com/People-at-Risk>
877-434-6384

Autism Society - <http://www.autism-society.org/>

Autism Spectrum Disorder Risk Management - <http://www.autismriskmanagement.com>

My Precious Kids – Child Safety Products - <http://www.mypreciouskid.com>

**WEST VIRGINIA SERVICES FOR CHILDREN and
ADULTS WITH AUTISM SPECTRUM DISORDER
AND THEIR FAMILIES**

A Brief History of Autism Services in West Virginia

Many people may not know that West Virginia has a rich history grounded in providing services for individuals with ASD and their families. Autism pioneer Dr. Ruth Sullivan came to Huntington, West Virginia in the 1970's and initiated several "firsts" in the field. She was active in working with Congress to establish the first legislation that mandated ALL children are entitled to a free appropriate public education in the least restrictive environment (PL 94-142). Prior to that, there was no mandate that stated children with special needs should attend public school. Dr. Sullivan also recognized that autism was a misunderstood condition and that the public, including educators, knew little about it. It was common for people to ask her about her "artistic" son.

Prior to coming to Huntington, Dr. Sullivan and several other parents formed the National Society for Autistic Children, now known as the Autism Society of America. She operated the only Autism Hotline in the nation from her home. In the late 1970's and early 1980's, when the de-institutional movement was occurring, she recognized the need for families to receive appropriate supports and education in order to keep their children in their natural home. Dr. Sullivan conducted a needs assessment related to services available for families of children with autism and also assessed educators' knowledge about appropriate education for students with Autism Spectrum Disorder. The lack of availability of services and the lack of educator's knowledge about autism was evident. In 1983, Dr. Sullivan presented the findings to the West Virginia Legislature, and along with several other parents, lobbied for the creation of the West Virginia Autism Training Center to be housed at Marshall University. Today, this statewide center has served over 4,000 families and their children and has provided education and training to thousands of educators.

At the same, Dr. Sullivan established the Autism Services Center (ASC), a behavioral health center for developmental disabilities including Autism Spectrum Disorder. The ASC became a pioneer in providing quality group home living and now has many group homes in the Huntington area. In 1988, Dr. Sullivan's son, Joseph, became one of the individuals that Dustin Hoffman studied for his movie character, Rainman. Dr. Sullivan became a consultant on the film. Rainman premiered in Huntington, West Virginia at the historic Keith Albee Theater. The premier was attended by Hoffman and director Barry Levinson. Rainman became a critically acclaimed film and brought the term "autism" to the public.

Another first in autism in the nation occurred in 1999 when West Virginia became the first state in the nation to join the CDC's surveillance of autism study through a grant awarded to the WV Autism Training Center. Subsequently, West Virginia became the first state to establish autism as a reportable condition of childhood. In 2002, The WV Autism Training Center established its College Program for Students with Autism Spectrum Disorder, making it the first of its type in the nation. This program supports college degree seeking students with ASD as they navigate the social and academic aspects of college life. Beginning with one student in 2002, the program has grown to support nearly 70 students each semester, from all across the nation.

In 2011 West Virginia became the 25th state in the nation to enact autism insurance legislation. Through the hard work of parents and professionals, and after several years of lobbying for the law, the legislation passed. Work continued in 2012 to improve and correct some of the language in the law.

As every state in the nation struggles to provide appropriate and vitally needed services for individuals with ASD and their families and educators, it is important to remember that West Virginia has been a pioneer in so many areas. The work continues through the efforts of the agencies listed in this guide and through the collaborative efforts of WV Team Autism . The overarching goal of every state is to provide a seamless and coordinated system of service delivery that will increase the quality of life for those living with ASD and their families. Our work in West Virginia diligently continues as we strive to achieve that goal.

Service Options

Finding services that work best for your family and child can seem like a full time job. However, having the supports that work for you, meet your child's needs, as well as support your dreams for their future can be is the best of all worlds.

Finding those services with the best fit for you can be challenging but not impossible. It takes doing your homework, networking with other families and professionals, and always seeking out the answers to the questions you have.

This section of our guide provides you with some general information on service options in West Virginia.

West Virginia Autism Training Center

In 1983, The West Virginia Legislature approved a bill to establish a state-wide center that would focus on providing education and training to parents, educators and others significant in the lives of West Virginians with a primary diagnosis of ASD. It was determined that the center would be housed at Marshall University. The West Virginia Autism Training (WV ATC) offers a variety of educational and resource services and provides these services in the local community where the individual resides.

Who is eligible for services? Any West Virginia resident with a diagnosis of Autism Spectrum Disorder can register for the services of the WV ATC. Individuals who were diagnosed with Autistic Disorder, Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) or Asperger's Disorder (diagnostic terms used prior to the current diagnostic manual) are also eligible for services.

What do I do to apply? Registering for services is easy. Just call 1-800-344-5115 (toll free in WV) or 304-696-2332 and ask to speak to the intake coordinator. The in-take coordinator will get some basic information from you and will send you an application packet. You will complete the application forms and submit a copy of the diagnostic report that shows your child has a diagnosis of Autism Spectrum Disorder, Autistic Disorder, PDD-NOS or Asperger's Disorder. Soon thereafter, you will receive a packet of information which will include your registry card. You will also receive a call from the intake/family resource coordinator to review the information contained in the packet and to answer any questions. She will explain the variety of services available and how you can use your registry card.

What services can I receive as a registered family? The following training and resource services are among those available at no cost to registered families:

- A lending library of books and DVDs related to ASD
- Participation in WV ATC workshops and in-service training at no cost
- Coaching sessions on a variety of topics (conducted by our family resource coordinator by phone)
- Information about national, state, and local community resources
- The Family Focus Positive Behavior Support process

Who can I contact for more information about the WV ATC? Call 1-800-344-5115 or 304-696-2332 for more information. Ask for the intake/family resource coordinator, they will be able to answer any questions or if you have a very specific question, they will connect you with the appropriate individuals.

Please visit the WV Autism Training Center website at
<http://www.marshall.edu/atc>

WV Birth to Three

WV Birth to Three is the state early intervention program. Early intervention services are described in the Individuals with Disabilities Education Act, which provides states with federal grants to support the activities of states in supporting its youngest citizens. The intent of WV Birth to Three services is to enhance the capacity of families to meet the needs of their children and to minimize the impact of a child's disabilities on their ability to participate in the daily life of the family.

The WV Birth to Three system provides home and community based education opportunities for families with young children, aged birth through age 2, who are experiencing one of the following:

- Developmental delay, or
- A physical or medical condition that is likely to result in a developmental delay, or
- Biological and/or environmental risk factors that may contribute to developmental delays.

Services and supports from WV Birth to Three are focused on the priorities and concerns of families and should address the unique needs of each individual child. When a child is referred to the WV Birth to Three system a comprehensive evaluation and assessment of the child's strengths, challenges and needs for support across the everyday activities and routines of the child and family. If the child is determined eligible for the WV Birth to Three system an Individualized Family Service Plan (IFSP) is developed which will spell out the outcomes the family and team will be working toward as well as the services and supports that will be provided in collaboration with the family.

Please visit the WV Birth to Three website at
<http://www.wvdhhr.org/birth23/>

You will find contact information for the Regional Offices of WV Birth to Three at
<http://www.wvdhhr.org/birth23/files/RAUmap2015.pdf>.

Public Education

Special education services pick up where early intervention services leave off, at age 3. Your county school district provides these services through their special education department. The focus of special education is different from that of early intervention. While early intervention addresses your child's overall development, special education focuses on providing your child with an education, regardless of disabilities or special needs. The document that spells out your child's needs and how these needs will be met is the **Individualized Education Program (IEP)**. Like the IFSP, the IEP describes your child's strengths and weaknesses, sets goals and objectives, and details how these can be met. Unlike the IFSP that focuses on supporting the child and family in home and community settings, the IEP is almost entirely related to how the school district will support your child in learning and functioning within the school environment.

Special Education Services – For Children Ages 3 - 22

The Individuals with Disabilities Education Act of 2004, Public Law 108-446, (IDEA 2004) and the IDEA regulations (34 CFR Part 300), require that States set forth policies and procedures to demonstrate that the a goal has been established providing full educational opportunity to all students with disabilities who are residents, aged birth through twenty-one years of age and a detailed timetable for accomplishing that goal. West Virginia is diligently working to ensure full educational opportunities for all students with disabilities, aged birth through twenty -one years of age. The State works toward the realization of this goal through the implementation of, and compliance with, IDEA 2004 and any subsequent reauthorization, state policies and procedures, and it's monitoring system.

Accessing Services: Your Child's Rights for Public Education

Every child has the right to a free appropriate education. The Individuals with Disabilities Education Act (IDEA), enacted in 1975, mandates a public education for *all* children and makes the schools responsible for providing the supports and services that will allow this to happen. The law mandates that the state provide children with a free appropriate public education that meets his or her unique individual needs. In addition, the IDEA legislation has established an important team approach and a role for parents as equal partners in the planning for an individual child, and promotes an education in the least restrictive environment. In addition to IDEA, there are other laws that provide guidance to schools and protections for students, these include:

- Americans with Disabilities Act of 1990 (ADA) sets forth, as a civil right, protections and provisions for equal access to education for anyone with a disability
- Section 504 of the Rehabilitation Act of 1973 is another civil rights law that prohibits discrimination on the basis of disability in programs and activities, public and private that receive federal financial assistance.

What is a "Free and Appropriate Public Education" (FAPE)?

A free appropriate public education (FAPE) must be available to all students residing in WV between the ages of three and twenty-one, inclusive, who are eligible for special education services. Each word in this phrase is important, but "appropriate" is the one that relates specifically to your child with special needs. FAPE is individually determined for each student, based upon their unique needs that will allow them to make educational progress. Although you and your child's teachers or therapists may want to provide your child with the best and optimal programs and services, the school district is simply required to provide an appropriate education. FAPE must include special education services in the least restrictive environment (LRE) and may include related services, transition services, supplementary aids and services, and/or assistive technology devices and services. Districts must also ensure that students have available to them the variety of education programs and services available to students without exceptionalities including art, music, industrial arts, consumer and homemaking education, and vocational education. One of the challenges here is working with the school district to determine what is appropriate and, therefore, what will be provided for your child. This is a collaborative process, and may require considerable negotiation in order to secure the appropriate services from the school.

What is “Least Restrictive Environment” (LRE)?

IDEA also provides that children with disabilities are entitled to experience the “least restrictive environment” in schools. This means that eligible students must be educated with general education students in the general education classroom, in their home school, to the maximum extent appropriate. Removal from the general education environment occurs only when the nature or severity of the exceptionality is such that education in general classes and other settings with general education students cannot be achieved satisfactorily even with the use of supplementary aids and services. This does not mean that every student has to be in a general education classroom, but the objective is to place the student in as natural a learning environment as possible, within his home community.

The participation of children with disabilities in the general education environment is often referred to as “mainstreaming” or “inclusion.” Inclusion does not mean that a child with special needs should be placed into a general education setting just like a typical learner; a variety of special education supports should be provided in order to create a successful environment and positive experience for everyone involved. Careful planning and training are essential to providing modifications or accommodations, and to successfully situating a child with a disability in the least restrictive setting. In determining an appropriate placement in the LRE, the IEP Team begins with the general education environment with supplementary aids and services. If the student’s IEP cannot be implemented in that environment with an expectation of reasonable progress on and achievement of IEP goals, a placement on the continuum of placement options providing less education with students without disabilities may be considered. An eligible student is not to be removed from age-appropriate general education classrooms solely because of needed accommodations and modifications to the general education curriculum. The IEP must explain the extent, if any, to which the student will not participate in the general education classroom, the general education curriculum, or extracurricular or other nonacademic activities and indicate the percentage of time in general and special education.

Participation in Nonacademic and Extracurricular Services and Activities: The IEP Team determines the supplementary aids and services appropriate and necessary for the student to participate with students without disabilities in nonacademic and extracurricular services and activities to the maximum extent appropriate. These services and activities may include, but are not limited to, meals, recess, field trips, counseling services, athletics, transportation, health services, recreational activities, special interest groups or clubs sponsored by the district, referrals to community agencies, career development and assistance in making outside employment available.

Parent involvement in education has proven to be a key factor in the success children achieve in school, but not every parent knows how to be involved and not every teacher or school administrator knows how to encourage participation from families. Connecting the dots of communication between home and school has become an important focus for the WV Department of Education, Office of Special Programs.

Please visit the WV Department of Education website to discover contact information for your County Special Education Director - <http://wvde.state.wv.us/osp/contactosecounty.htm>
and
Parent Educator Resource Center (PERC) – <http://wvde.state.wv.us/osp/perc.html>

Information in this section is adapted from the following:

- Autism Spectrum Disorder Speaks (2013). 100 day kit. Retrieved from [http://www.Autism Spectrum Disorderspeaks.org/family- services/tool-kits/100-day-kit](http://www.AutismSpectrumDisorderspeaks.org/family-services/tool-kits/100-day-kit).
- WV Department of Education (2012). Education for students with exceptionalities. Retrieved from <http://wvde.state.wv.us/>.

Center For Excellence in Disabilities

Established in 1978, the Center for Excellence in Disabilities (CED) is located in Morgantown, West Virginia and has a satellite office in Big Chimney, West Virginia with staff located in offices across the state to better serve clients in their communities. The CED is a unit within West Virginia University (WVU), Health Sciences, and because of the placement within the University, has access and alignment within the Schools of Pharmacy, Public Health, Nursing, Medicine and Dentistry. See more at: <http://cedwvu.org>

Positive Behavior Support Project

Building the capacity of those who support individuals with challenging behavior who have developmental disabilities, traumatic brain injuries, and co-existing disorders is the primary focus of the PBS Project. We primarily accomplish capacity building through training and continuing education opportunities, technical assistance, and mentoring. Additionally, we offer short-term consultation to a very limited number of individuals statewide and person centered planning to families who need help addressing challenging behavior or defining long-term goals.

What is PBS? - Positive Behavior Support (PBS) is an inclusive approach for teaching new skills to replace challenging behaviors and redesigning the living environment to enhance an individual's quality of life. PBS operates from a person-centered values base, allowing the participant to guide team decisions about their lives. This approach is positive, proactive, and focuses on preventing challenging behaviors before they occur. PBS utilizes information from functional behavioral assessments to develop behavior support plans for individuals who have challenging behaviors.

The Positive Behavior Support Project is funded through a grant with the West Virginia Department of Health and Human Resources, Bureau for Behavioral Health and Health Facilities. See more at: <http://pbs.cedwvu.org>, call 304-293-7294, or email pbs@hsc.wvu.edu.

Parent Network Specialist Project

PNS primarily assists children and families enrolled in the CSHCN program with educational, vocational and transitional services. This statewide project features five Specialists who are parents of children of varying ages who have a disability and are located in geographically strategic areas of West Virginia. These Parent Network Specialists provide one-on-one information and referral services and follow-up to families who have a child with a disability. Parent Network Specialists receive on-going training in pertinent areas such as Title XIX MR/DD Waiver and Medicaid processes, HIPAA regulations, the roles of other agencies, and the availability of resources.

The Parent Network Project has produced a Care Notebook for parents and other family members caring for a child with a disability. The Care Notebook is a case management tool and a resource guide, which can be used as a single depository of information (e.g., medical, emergency contacts, and care provider contact information) that parents can have available to take to appointments or to leave at home as a reference for care providers. The annotated resource guide section provides contact information for disability-related agencies and services.

The Parent Network Project is funded by the WV Division of Health and Human Resources, Office of Maternal Child and Family Health, Children with Special Health Care Needs. See more at <http://pns.cedwvu.org> or call 304-293-4692 extension 60689.

WV Assistive Technology Clinic

The West Virginia Assistive Technology System (WVATS) is the designated lead agency that works to enhance the lives of all West Virginia residents with disabilities, including older West Virginians and the families of people with disabilities. By providing access to and help with the acquisition of assistive technology devices and services, WVATS can offer West Virginians with disabilities an opportunity for choice, control and independence at home, work, school, play, and in their neighborhoods.

WVATS strives to bring assistive technology into the lives of all state residents with AT needs, through its programs and services. **Assistive Technology (AT)** is any device used to perform tasks that would otherwise be difficult or impossible. These devices can be as complex as computers with screen reading software or as simple as Velcro used in place of buttons or shoe laces.

WVATS receives federal dollars to conduct AT activities and is overseen by a Consumer Advisory Council, comprised of individuals and agency staff who represent all ages, disabilities, and geographic regions of the state.

Find out more how WVATS improves access to and the acquisition of assistive technology (AT) in:

- Employment
- Education
- Information Technology & Telecommunication
- Community Living

The project described was supported by Grant Number 90AG0011 from the Administration for Community Living. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS).

See more at <http://wvats.cedwvu.org/> or call 800-841-8436.

Feeding and Swallowing Clinic

The Feeding and Swallowing Clinic provides interdisciplinary assessments of infants, children and adolescents who have feeding, eating, or swallowing problems. Assessments are completed by a team of professionals in the areas of nutrition, occupational therapy, behavioral psychology, speech-language pathology, and social work.

The Objectives Of The Clinic Are:

- Improve eating skills and behaviors
- Improve physical growth and development
- Improve the nutritional status of children

The Clinic Assists Families In:

- Promoting self-feeding
- Increasing acceptance of food types and textures
- Transitioning from tube feeding to eating by mouth
- Improving sucking, chewing, biting and/or swallowing skills
- Improving meal-time behaviors
- Improving the quality of the diet

Appointments and Clinic Visits

- Call 304-293-4692 to make an appointment. Once scheduled, a packet of information is sent to the family.
- Families are welcome to bring caregivers and professionals who work with their children to the clinic. Visits usually take between one and two hours.
- The Feeding Clinic has family friendly clinic rooms. The Feeding Team is present for each visit, with the team members usually taking turns going into the clinic to interact with and evaluate each child. Family members typically stay with their children in the clinic room for the entire visit.
- Techniques in feeding and positioning may be demonstrated; behavioral strategies, assistive technology, nutrition and other issues may be discussed. Families receive written reports several weeks after their visit. See more at <http://nutrition.cedwvu.org/feeding-swallowing-clinic/>.

Intensive Autism Service Delivery Clinic

Autism Spectrum Disorder is a lifelong neurobiological disorder that impairs a person's ability to communicate and relate to others. The CDC estimates that 1 in 68 children have an Autism Spectrum Disorder. Boys are four times more likely than girls to be affected by autism. Autism is the fastest growing developmental disability with a growth rate of 10% to 17% annually.

The Intensive Autism Service Delivery Clinic (IASD) sees children with a diagnosis of Autism Spectrum Disorder from the ages of two to six. One of the main goals is to help the child "learn to learn" through intensive, individualized one-to-one intervention. Having an impact on these skills at this young age has been shown to have a profound positive impact for children with Autism Spectrum Disorder through their lifetimes.

What Services Are Offered? The Clinic is currently providing very successful one-to-one behavioral services to a limited number of children, ages 2 to 6 years, who have been diagnosed with an autism spectrum. All treatment is based on the science of applied behavior analysis, combining discrete trial training with naturalistic and incidental teaching. Young children served by the clinic receive between 7 and 35 hours of free services per week. They each have an individualized curriculum updated weekly and are taught by at least two different therapists (which helps the skills to generalize) throughout each day.

The Clinic Helps Children To: "Learn how to learn" through evidence-based behavioral interventions. Learning assessments are completed on each child and individualized curriculum is developed and implemented to assist in skill building in all areas of development.

Where Are Services Offered? The Intensive Autism Service Delivery Clinic is located in Morgantown at the Center for Excellence in Disabilities.

How Much Do These Services Cost? There is **no** charge for these services at the time.

Who Provides These Services? All programming is supervised and overseen by a Board Certified Behavior Analyst (BCBA) who has experience in working with young children with autism, and is implemented by trained students or volunteers who are seeking experience in this field. Many of our student volunteers are from the Behavioral Intervention Program in the Department of Psychology-the only such program in the state-that requires 70+ hours of supervised hands-on experience in order to sit for their BCBA licensing exam.

Who Is Eligible For These Services? Children with a diagnosis of autism from of the ages of two to six. The Clinic is currently limited to five children on rotating schedules due to space requirement and the availability of trained therapists.

Who provides these services? Our knowledgeable staff!

How do I make an appointment or make a referral for services? Call toll free at 888-829-9426 to be put on the waiting list. See more at <http://cedwvu.org/intensive-autism-service-delivery-clinic/>.

Early Childhood Lending Library

The Early Childhood Lending Library contains numerous resources for parents, educators, students, service providers and the general public. Resource topics include a variety of issues around pregnancy and early childhood development, family health, disability information, assistive technology and many others! Items available for loan include:

- Assistive Technology
- Books, Journals and Magazines
- Videos
- Toys
- Training Curricula

To see what resources are available, visit the Virtual Loan Library at <http://cedwvu.org/resources/early-childhood-resource-lending-library/>. Items may be borrowed from the Library for a period of 30 days. A loan agreement outlines the terms of the lending policy and is available by calling 800-642-9704. Items can be mailed to you at no cost. However, you are responsible for paying mailing costs to return items you have borrowed. You may also visit the library, Monday through Friday 8:00 am – 4:00 pm.

Intellectual/Developmental Disability Waiver

WV I/DD Waiver Program (formerly the MR/DD Waiver Program) provides services that instruct, train, support, supervise, and assist individuals who have intellectual disabilities or developmental disabilities in achieving the highest level of independence and self-sufficiency possible in their lives.

The I/DD Waiver Program provides services in natural settings, homes and communities where the member resides, works, and shops instead of ICF/IID facilities.

For More Information Contact Program Manager, I/DD Waiver Program

Tania R. Hardy
Bureau for Medical Services
350 Capitol Street, Room 251
Charleston, WV 25301
Phone: (304) 356-4853
Email: Tania.R.Hardy@wv.gov

WV Department of Vocational Rehabilitation

The Division of Rehabilitation Services is West Virginia's primary vocational rehabilitation resource for people with disabilities who want to work. DRS helps many West Virginians prepare for careers consistent with their interests, needs and abilities. DRS helps many more to maintain their current employment if a disability is making it difficult to continue working.

Vocational rehabilitation provides direct, personalized services. During the vocational rehabilitation process, a counselor will work with you one-on-one to plan an individualized program that leads to paid employment. You will actively participate in planning your services, and how those services will be delivered. Services may include evaluation, restoration, vocational training, occupational tools and equipment, assistive technology and job placement assistance. Work-related counseling is the most essential service offered by DRS. A trained counselor will be available throughout the rehabilitation process to answer questions, help with problems and offer guidance toward achievement of your rehabilitation goals. A successful rehabilitation may take anywhere from several months to several years.

Are You Eligible?

Eligibility is based on three factors:

- you have a physical or mental condition that interferes with your ability to get or keep a job;
- you can benefit from services in terms of an employment outcome; and
- you need vocational rehabilitation services to get or keep a job.

To determine your eligibility for vocational rehabilitation services, an initial interview is set up between you and a rehabilitation counselor. If you wish, a friend or family member may accompany you. Your counselor will talk with you about your career plans and the services you feel are necessary to reach an employment goal. The counselor will ask about your work history, education, and disability.

If possible, bring any reports (medical, psychological, etc.) from people who have previously provided services to you. You should also bring your work history. This will help your counselor more quickly determine your eligibility for DRS services.

DRS is required by law to maintain your confidentiality. All personal information provided by you or any other source is strictly confidential and won't be released to anyone (other than your legal guardian, if applicable) without your written consent.

Making a Plan

After you have been determined eligible for services, the next step will be to develop an Individualized Plan for Employment (IPE) with your counselor. The IPE is an agreement between you and DRS that describes the services that will be provided for you to meet your employment goal.

Evaluation, counseling, job development, and placement services are provided at no cost to you. You may be required to share the cost of some services, but your rehabilitation counselor will talk to you about any costs before services start.

Basic services may include:

- Work-related counseling and guidance
- Evaluation services may include vocational, medical, psychological or educational evaluations
- Information and referral services
- Accessibility and worksite evaluations and accommodations
- Assistive technology
- Restoration services may include treatment of medical or psychological conditions; orthotic and prosthetic devices; or physical, occupational, speech, or hearing therapy
- Vocational training may include vocational school, college, technical or business school or on-the-job or supported employment training
- Employment services may include resume writing and interview skills development, job search and placement

Your Right to Appeal

Your rehabilitation counselor will explain your rights at various times during the vocational rehabilitation process. If you have been denied services and you disagree with that decision, you can file an appeal. If you need help preparing the appeal, you can call the Client Assistance Program (CAP) operated by Disability Rights, WV. You may contact a CAP representative directly through the Disability Rights, WV at 1-800-950-5250. This is a toll-free call within West Virginia.

Apply For Services

If you are interested in applying for services, you may contact a DRS office near you or submit a request online at <http://www.wvdrs.org/index.cfm>. Contact information is located on the web at <http://www.wvdrs.org/index.cfm?fuseaction=home.displaystory&groupID=88&itemid=26>.

Financial Resources

Adequate financial resources are key to a family accessing supports and services to maximize the health, educational, and independence of their children with Autism Spectrum Disorder.

West Virginia Children's Health Insurance Program

WVCHIP was created through the amendment of the Social Security Act thus creating Title XXI "State Children's Health Insurance Program". Children first began enrolling in the WVCHIP in July 1998 and by June 2011 over 135,433 children had obtained health care coverage through this plan.

WVCHIP covers children from birth through the age of 18. It pays for a full range of health care services for children including: doctor visits, check-ups, vision and dental visits, immunizations, prescriptions, hospital stays, mental health and special needs services.

Your child/children may be eligible for WVCHIP if they:

- Reside in the State of West Virginia;
- Are age 18 or younger;
- Are not eligible for West Virginia Medicaid;
- Meet WVCHIP family Income Guidelines;
- Are United States citizens or qualified aliens (Children who are not US citizens must provide verification of their alien status.);
- Are presently not covered under any other health insurance plan.

To apply: Applying for WVCHIP can be completed entirely in your own home. Choose one of the options below that best fits your needs:

- Visit <http://www.chip.wv.gov/Pages/default.aspx> for additional information on income guidelines and to download an application: **Note:** Please mail printed application to your county DHHR office;
- Visiting <https://www.wvinroads.org/selfservice/> to apply online; **(Preferred method)**
- Visit <https://www.healthcare.gov/> to apply and see what you and /or your child are eligible for;
- Calling the toll-free helpline at 1-800-318-2596 for assistance if you have questions that aren't on the website or to access TDD and translation services

WV MEDICAID PROGRAM

Medicaid provides medical care to individuals who otherwise may not be able to afford the care. A variety of services are provided, according to state and federal guidelines, depending upon the individual or family circumstances. Recipients of Supplemental Security Income (SSI) automatically qualify for Medicaid. There are many ways to qualify to receive Medicaid.

HOW TO QUALIFY FOR MEDICAID

Medicaid Citizenship and Identity Requirements

All Medicaid applicants or recipients will be asked to provide documents to verify U.S. citizenship and identity. The following documents listed are some of those you may use to prove citizenship and/or identity.

Proof of Citizenship and Identity (No other proof required):

- U.S. Passport

Proof of Citizenship (Separate Proof of Identity Required):

- A U.S. public birth record
- A final adoption decree; evidence of civil service employment

Proof of Identity:

- School Identification Card with a photograph

Intellectual/Developmental Disability – I/DD Waiver

I/DD Waiver Program (formerly the MR/DD Waiver Program) provides services that instruct, train, support, supervise, and assist individuals who have intellectual disabilities and/or developmental disabilities in achieving the highest level of independence and self-sufficiency possible in their lives. The I/DD Waiver Program provides services in natural settings, homes and communities where the member resides, works, and shops instead of ICF/MR facilities.

Children with Disabilities Community Services Program – CDCSP

CDCSP is a West Virginia optional program that provides Medicaid benefits to severely disabled children who meet the program's eligibility requirements. It is administered by the Bureau for Medical Services (BMS) and approved by the Centers for Medicare and Medicaid Services (CMS), the federal agency responsible for I/DD Waiver. The CDCSP is an alternative to institutionalization and provides medically necessary services that are community-based and costs less than institutional services.

How to Apply For Medicaid

Contact the local DHHR office that serves your county and/or you can apply online by going to: <https://www.wvinroads.org/inroads/PGM/ASP/SC001.asp>

Social Security Disability Income for Children

This provides information for the parents, caregivers or representatives of children under age 18 who have disabilities that might make them eligible for Supplemental Security Income (SSI) payments.

Supplemental Security Income (SSI) Payments for Children with Disabilities

SSI makes monthly payments to people with low income and limited resources. Your child under age 18 can qualify if he or she meets Social Security's definition of disability for children, and if his or her income and resources fall within the eligibility limits. The amount of the SSI payment is different from one state to another because some states add to the SSI payment. Your local Social Security office can tell you more about your state's total SSI payment.

SSI Rules about Income and Resources

When the Social Security Administration (SSA) decides if your child can get SSI, they consider your child's income and resources. They also consider the income and resources of family members living in the child's household. These rules apply if your child lives at home.

If your child's income and resources, or the income and resources of family members living in the child's household, are more than the amount allowed, the SSA will deny the child's application for SSI payments.

SSI Rules about Disability

Your child, birth to age 18, must meet all of the following requirements to be considered disabled and therefore eligible for SSI:

- The child must have a physical or mental condition, or a combination of conditions, that result in "marked and severe functional limitations." This means that the condition(s) must very seriously limit your child's activities.
- The child's condition(s) must have lasted, or be expected to last, at least 12 months; or must be expected to result in death.

If your child's condition(s) results in "marked and severe functional limitations" for at least 12 continuous months, we will find that your child is disabled. But if it does not result in those limitations, or does not last for at least 12 months, the SSA will find that your child is not disabled.

Providing Information About Your Child's Condition

When you apply for benefits for your child, the SSA will ask you for detailed information about the child's medical condition and how it affects his or her ability to function on a daily basis. They also will ask you to give permission for the doctors, teachers, therapists and other professionals who have information about your child's condition to send the information to us. If you have any of your child's medical or school records, please bring them with you. This will help speed up the decision on your application.

What Happens Next?

The SSA sends all of the information you give us to the Disability Determination Services in your state. Doctors and other trained staff in that state agency will review the information, and will request your child's medical and school records, and any other information needed to decide if your child is disabled.

If the state agency cannot make a disability decision using only the medical information, school records and other facts they have, they may ask you to take your child for a medical examination or test. We will pay for the exam or test.

Immediate SSI Payments to the Child

It can take three to five months for the state agency to decide if your child is disabled. However, we consider certain medical conditions so limiting that we expect any one of them to disable a child. In these cases, we make SSI payments right away and for up to six months while the state agency decides if your child is disabled.

If your child has one of the limiting conditions that is expected to disable a child, he or she will get SSI payments right away. However, the state agency may finally decide that your child's disability is not severe enough for SSI. If that happens, you will not have to pay back the SSI payments that your child got.

How to Contact Social Security Administration

You may contact SSA directly by the website <http://www.ssa.gov/agency/contact/>. In addition to the website, you can call toll-free, using 800-772-1213 to get specific questions answered from 7:00 am to 7:00 pm Monday through Friday.

WV Insurance Legislation

The Autism Spectrum Disorder insurance mandate went into effect on July 1, 2011 and requires companies to cover Autism Spectrum Disorder treatments on plans issued or renewed after January 1, 2012. Any treatment that is medically necessary and prescribed by a licensed physician or licensed psychologist is covered.

Applied Behavioral Analysis (ABA) services are expressly covered by the mandate.

The mandate applies to all individuals diagnosed with an Autism Spectrum Disorder by age eight or younger who are currently 18 months to 18 years of age. According to the current mandate, Autism Spectrum Disorder includes any pervasive developmental disorder, including autistic disorder, Asperger's syndrome, Rhett syndrome, childhood disintegrative disorder, or pervasive developmental disorder as defined in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association."

This mandate does not apply to Medicaid/medical cards, self-funded plans, federal employees, insurance plans that originate outside of WV or companies with 25 or fewer employees. Many policies, such as those for coal mines and medical facilities, are self-funded. Asking if a policy is self-funded should be one of the first questions families ask when calling to access the Autism Spectrum Disorder benefit.

Family and Community Support Program

The Bureau for Behavioral Health and Health Facilities' (BBHFF) purpose for creating the Family and Community Support Program throughout West Virginia is to assist individuals to live at home and in the community by identifying resources and aligning processes aimed at supporting persons with disabilities in integrated settings, with emphasis on individualizing and maximizing community resources. Many of the challenges and opportunities experienced by people seeking to live a life of quality in the community are common, regardless of disability. Individuals and families want and need information about resources, access to services and flexible funding to address emergency and/or extraordinary needs, and support from peers and professionals.

The Family and Community Support Program and Community Engagement Program's enhance the quality of life for individuals who live in home and community settings. Based on this common expectation, and in light of complex fiscal times, the BBHFF offers a newly envisioned Family and Community Support model to sustain and eventually grow support resources for individuals statewide. The model relies on a regional infrastructure of Family Support Councils, volunteer and staff engagement of families and resources, and a pool of flexible support funds and Community Engagement programming.

Goals for the Family and Community Support Program include:

1. Strengthen the role of the Regional Family Support Councils. Beyond the distribution of stipends as a "fund of last resort," the Councils will expand their capacity for providing resource and other knowledge geared to help families learn about and navigate existing community-based and statewide services and resources.
2. Restructure the Regional Family Support Coordinator's role to enable networking with various stakeholders to gain and share knowledge of available resources, identify gaps, and promote development of resources.
3. Support the Community Engagement Specialists to help families develop a support plan and navigate the service system.
4. Support and empower families to make their own informed decisions, and become effective self-advocates.
5. Advise State and Regional Councils and the larger intellectual/developmental disabilities system about family issues to promote systems change.

A Family and Community Support application can be obtained by calling your service coordinator/case manager or Family Support Coordinator or by clicking <http://www.dhr.wv.gov/bhff/Sections/programs/ProgramsPartnerships/IDD/Documents/Family%20Community%20Support/FCSP%20Application%20Updated%205-28-15.pdf> .

Family and Community Support does have a policy that you cannot prepay for items and receive funds as reimbursement. Each agency establishes their application policies so they may differ across the state. In addition, each agency does not receive the same amount of funding.

West Virginia State Tax Department



WEST VIRGINIA CHILDREN WITH AUTISM SPECTRUM DISORDER

TRUST BOARD CHECKLIST FOR APPLICANTS

General Information

West Virginia Code §§44-16-1 et seq. establishes the West Virginia Children with Autism Spectrum Disorder Trust Board (Board) to qualify trust accounts created to provide support for a child with Autism Spectrum Disorder. When a trust is qualified under this statute the parent or guardian establishing the trust becomes eligible for certain tax benefits. To qualify, the person designated as the beneficiary of the trust must meet certain eligibility requirements. If the Board determines that the beneficiary is eligible, we will perform the second level of eligibility review to determine whether the trust itself meets the statutory standards. If both eligibility standards are met – eligibility of the beneficiary and eligibility of the trust – the Board will issue a ruling that the eligibility requirements are met, allowing the parent or guardian eligibility to receive the tax benefits.

It is important to read the statute and observe its definitions in attempting to qualify a trust for these purposes.

Eligibility of the Individual

Applicable Definitions

- " 'Autism Spectrum Disorder' means a complex developmental disability and spectrum disorder, whose diagnosis must be clinically confirmed by qualified physicians and psychiatrists after extensive examination and testing, defined by a certain set of behaviors and symptoms which affects a person's ability to communicate and interact with others." West Virginia Code §44-16-1 (a)
- " 'Child with Autism Spectrum Disorder' means a child, under the age of eighteen, who has been clinically diagnosed as having Autism Spectrum Disorder to a degree to which it results in a moderate or severe impairment in two or more areas of daily living, as the terms 'moderate impairment', 'severe impairment' and 'daily living' are defined under Title II or Title XVI of the Social Security Disability Act, or a child who has been clinically diagnosed with Autism Spectrum Disorder and has been determined to be disabled under either Title II or title XVI of the Social Security Disability Act for any reason." West Virginia Code §44-16-1 (c)

1. Was the beneficiary of the trust a person under the age of eighteen years at the time that the trust was created? *If the answer is yes, please provide a certified copy of the child's birth certificate.*
2. Has the beneficiary of the trust been diagnosed with Autism Spectrum Disorder? *If the answer is yes, please provide a statement from a physician to confirm the diagnosis. Note: The term "physician" includes psychiatrists, osteopathic physicians, and medical doctors.*
3. Has the beneficiary of the trust qualified for Social Security Disability benefits or SSI as a disabled individual? *If the answer is yes, please provide documentation from the Social Security Administration. If the answer is no, please proceed to Question 4.*
4. Has the beneficiary of the trust produced evidence that they have a condition (Autism Spectrum Disorder) or multiple conditions (one of which is Autism Spectrum Disorder) that would meet the Social Security Administration's definition of moderate or severe impairment on daily living activities? *If the beneficiary of the trust has not qualified for Social Security Disability benefits or SSI as a disabled individual, the person seeking to qualify the trust must present clinical evidence that would allow the Board to conclude that the beneficiary's condition meets the standards established by the Social Security Administration (SSA) for a moderate or severe impairment in two or more areas of daily living.*
 - a. SSA defines "autistic disorder" as being "characterized by qualitative deficits in the development of reciprocal social interaction, in the development of verbal and nonverbal communication skills, and in imaginative activity. Often, there is a markedly restricted repertoire of activities and interests, which frequently are stereotyped and repetitive."

- b. SSA regulations state that the required level of severity for an autistic disorder in a child is met when there are medically documented findings of “qualitative deficits in the development of reciprocal social interaction AND qualitative deficits in verbal and nonverbal communication and in imaginative activity AND markedly restricted repertoire of activities and interests. Additionally, there are other age group-specific requirements that must be met.
1. For older infants and toddlers (age 1 to attainment of age 3) the autistic condition must result in at least one of the following:
 - (a) Gross or fine motor development at a level generally acquired by children no more than one half the child’s chronological age, documented by an appropriate standardized test or other medical findings, OR
 - (b) Cognitive/communicative function at a level generally acquired by children no more than one half the child’s chronological age, documented by an appropriate standardized test or other medical findings of equivalent cognitive/communicative abnormality, such as the inability to use simple verbal or nonverbal behavioral to communicate basic needs or concepts OR
 - (c) Social function at a level generally acquired by children no more than one-half the child’s chronological age, documented by an appropriate standardized test or other medical findings of an equivalent abnormality of social functioning, exemplified by serious inability to achieve age appropriate autonomy as manifested by excessive clinging or extreme separation anxiety OR (d) Attainment of development or function generally acquired by children no more than two-thirds of the child’s chronological age in two or more areas covered by (a), (b), or (c), as measured by an appropriate standardized test or other appropriate medical findings.
 2. For children from age 3 to attainment of age 18 years the autistic condition must results in at least two of the following conditions:
 - (a) Marked impairment in age-appropriate cognitive communicative function, documented by medical findings (including consideration of historical and other information from parents or other individuals who have knowledge of the child, when such information is needed and available) and including, if necessary, the results of appropriate standardized psychological tests, or for children under age 6, by appropriate tests of language and communication OR
 - (b) Marked impairment in age-appropriate social functioning, documented by history and medical findings (including consideration of information from parents or other individuals who have knowledge of the child, when such information is needed and available) and including, if necessary, the results of appropriate standardized tests OR
 - (c) Marked impairment in age-appropriate personal functioning, documented by history and medical findings (including consideration of information from parents or other individuals who have knowledge of the child, when such information is needed and available) and including, if necessary, appropriate standardized tests OR
 - (d) Marked difficulties in maintain concentration, persistence, or pace.
- c. It is important to note that the criteria listed above apply to those individuals whose disability is caused by the effects of Autism Spectrum Disorder alone. Children who have multiple medical or psychological conditions, one of which is Autism Spectrum Disorder, may also qualify under criteria specific to their condition or conditions. The person seeking to establish their qualification must provide medical documentation that would enable the Board to conclude that the child meets the appropriate SSA criteria for their specific condition or conditions. Information on SSA disability criteria can be found at <http://www.ssa.gov/disability/>.

Eligibility of the Trust

Applicable Definitions

- “ ‘Qualified trust for a child with Autism Spectrum Disorder’ means a trust account for a child with Autism Spectrum Disorder that (1) Is established at a national bank, a state bank of a state of the United States or a trust company that at all times is no less than adequately capitalized as determined by standards adopted by United States banking regulators and that is either regulated by state banking laws of a state of the United States or is a member of the Federal Reserve System; and (2) has been approved by the West Virginia Children with Autism Spectrum

Disorder Trust Board in accordance with this article." West Virginia Code §44-16-1 (f)

- "'Qualified trustee' means any person authorized by the laws of this state or of the United States to act as a trustee who has been approved by the board to serve as the trustee of a qualified trust for a child with Autism Spectrum Disorder." West Virginia Code §44-16-1 (g)
1. Has a valid trust been created to benefit the individual with Autism Spectrum Disorder? If the answer is yes, please provide a copy of the trust document.
 2. Are the allowable expenses to be paid by the trust for the benefit of the individual also allowable expenses under West Virginia Code §44-16-2? This will be determined by reading the trust document in conjunction with the definitions of allowable expenses in the statute.
 3. Is the trust established in accordance with West Virginia Code §44-16-1 (f) at an appropriate bank or trust company? Please provide evidence that the institution meets the standards provided in the statute.
 4. Does the person named as the trustee meet the criteria in West Virginia Code §44-16-1 (g)? Please provide evidence that the trustee meets the standards provided in the statute.
 5. Does the trust authorize disbursements after the beneficiary reaches the age of eighteen years? This should be apparent in the trust document provided.
 6. Does the trust also authorize disbursements at an earlier time if the parent or guardian who established the trust dies before the beneficiary of the trust reaches the age of eighteen years? This should be apparent in the trust document provided

To obtain the application for the WV Autism Trust Fund, please visit

<http://www.state.wv.us/taxrev/forms/ChildrenWithAutismTrustBoardChecklistForApplicants.pdf>.

National and State Resources

A variety of national and state resources have been included for you as you are beginning and/or continuing your journey to seek information, evidence based practices, and service options.

AUTISM SOCIETY



The Autism Society, the nation's leading grassroots Autism Spectrum Disorder organization, exists to improve the lives of all affected by Autism Spectrum Disorder. They do this by increasing public awareness about the day-to-day issues faced by people on the spectrum, advocating for appropriate services for individuals across the lifespan, and providing the latest information regarding treatment, education, research and advocacy. <http://www.autism-society.org/>

State and Local Affiliates of the Autism Society

Chapter/Group	Contact Information	Serving
Autism Society of West Virginia	http://autismwv.blogspot.com	Providing information, supporting research, and advocating for programs and services to enhance the lives of West Virginians living on the autism spectrum and those who support them.
Autism Society River City Organizers of the Annual Rally for Autism	http://www.autismsocietyrivercities.org	Counties served: <ul style="list-style-type: none"> • Cabell • Putnam • Wayne • Ashland, KY • Proctorville, OH
Northern Community Autism Chapter	http://www.facebook.com/pd/northernautismcommunity/about	Counties served: <ul style="list-style-type: none"> • Brooke • Hancock • Marshall • Ohio • Wetzel
Corridor Chapter of the Autism Society of WV	https://www.facebook.com/corridoraffiliateofaswv	Counties served: <ul style="list-style-type: none"> • Doddridge • Harrison • Lewis • Marion • Monongahela • Taylor
River Valley Autism Network	https://www.guidestar.org/profile/26-0896328	Counties served: <ul style="list-style-type: none"> • Jackson
Logan County Autism Association	lcaawv@gmail.com	Counties served: <ul style="list-style-type: none"> • Logan
Eastern Panhandle Indigo Children (EPIC)	http://www.epic-wv-autism.org	Counties served: <ul style="list-style-type: none"> • Jefferson
Autism Embassy	n.highly@aol.com	

Other Parent Supports

Autism Speaks - Autism Speaks was founded in February 2005 by Bob and Suzanne Wright, grandparents of a child with Autism Spectrum Disorder. Autism Spectrum Disorder Speaks is dedicated to funding research into the causes, prevention, treatments and a cure for Autism Spectrum Disorder; increasing awareness of Autism Spectrum Disorder spectrum disorders; and advocating for the needs of individuals with Autism Spectrum Disorder and their families. Their website houses information on current events in Autism Spectrum Disorder, research, advocacy and family services. <http://www.autismspeaks.org/>

OVERVIEW of WEST VIRGINIA STATE AGENCIES

West Virginia Autism Training Center - <http://www.marshall.edu/atc/>

The West Virginia Autism Training Center at Marshall University (WV-ATC) is a state funded, statewide center providing training, information and support to West Virginians with Autism Spectrum Disorder spectrum disorders of all ages, their families, educators, and other individuals involved in their lives. Their mission is "To provide support to individuals with Autism Spectrum Disorder as they pursue a life of quality". The main service delivery model is called Family Focus Positive Behavior Support (FFPBS). FFPBS includes person and family-centered planning, the development of a support team of individuals and the development and implementation of a comprehensive positive behavior support plan tailored specifically for the individual with an ASD. WV-ATC also offers a variety of other services including statewide training on topics related to ASD, a lending library, family coaching sessions by phone and connections to state and national resources. To qualify, an individual must be a resident of West Virginia and have a diagnosis of an Autism Spectrum Disorder spectrum disorder. Services of the WV ATC are at no cost to families.

Center For Excellence And Disabilities (CED) - <http://www.cedwvu.org/>

The Center for Excellence in Disabilities (CED) at West Virginia University (WVU) continues to work with consumers and state, local and federal agencies to realize opportunities and overcome challenges for people with developmental and other disabilities of all ages and their families. The Center, funded through the U.S. Department of Health and Human Services, Administration for Community Living, Administration on Intellectual and Developmental Disabilities, has services for people with disabilities throughout the state of West Virginia.

West Virginia Developmental Disability Council - <http://www.ddc.wv.gov>

The WV Developmental Disabilities Council is a 32 member organization that was established by an Executive Order of the Governor on March 6, 1972. The Council is authorized and funded by the Federal Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402). It is administratively supported by the WV Department of Health and Human Resources.

The Council's mission is to assure that West Virginians with developmental disabilities receive the services, supports and opportunities they need to achieve independence, productivity, integration and inclusion into the community. It does this in four major ways:

- including people with developmental disabilities and their families in the development of policies and programs;
- analyzing needs and advocates for improvements to the human service system;
- providing training and technical assistance to build competent and inclusive communities; and
- providing grants to community organizations to demonstrate innovative services and practice

Disability Rights of West Virginia - <https://www.drofww.org/>

Disability Rights of WV is the federally mandated protection and advocacy system for people with disabilities in West Virginia. DRWV is a private, nonprofit agency. Our services are confidential and free of charge. DRWV can provide technical assistance for special education.

Division Of Rehabilitation In West Virginia - <http://www.wvdrs.org/> - **Get ready to work!**

The West Virginia Division of Rehabilitation Services (DRS) is a state agency that serves West Virginians with disabilities. The mission of DRS is to enable and empower individuals with disabilities to work and to live independently.

DRS operates two major programs. The vocational rehabilitation program helps people with disabilities get or keep a job. For those who are unable to work, the Disability Determination Section (DDS) determines eligibility for Social Security disability benefits or Supplemental Security Income.

West Virginia Parent Information And Training (WVPTI) - <http://www.wvpti.org/>

West Virginia Parent Training and Information, Inc. (WVPTI) is a non-profit agency that operates a statewide federally funded Parent Training and Information Center, Family to Family and is the Family Voices of State Affiliate Organization for West Virginia. The programs and services of WVPTI, Inc. are based on the concept of parents helping parents, in special education programs and other areas.

The Arc of West Virginia - <http://www.thearc.org>

Services for individuals with Intellectual and Developmental Disabilities. Chapters in WV include: The Arc of West Virginia, The Arc of Harrison County, The Arc of the Mid-Ohio Valley, The Arc of Ohio County, and The Arc of Three Rivers.

Bureau For Behavioral Health And Health Facilities - <http://www.dhhr.wv.gov/bhhf>

Welcome to the Bureau for Behavioral Health and Health Facilities. Our mission is to ensure that positive meaningful opportunities are available for people with mental illness (children, adolescents, and adults), substance abuse, intellectual and developmental disabilities and those at risk. We provide support for individuals, families, and communities in assisting persons to achieve their potential and to gain greater control over the direction of their future. The Bureau recognizes the invaluable knowledge and experiences the consumers and families provide in helping to develop and improve services in West Virginia. The BBHFF operates under the auspices of the West Virginia Department of Health and Human Resources (WVDHHR). We envision a community that values and respects people and is responsive to their individual needs, wants and desires for the enrichment of their lives. We believe in integrity-based leadership that is flexible enough to respond to change that is guided by individuals, families, and communities.

Mountaineer Autism Project - <http://mountaineerautismproject.org>

Mountaineer Autism Project (MAP) is a nonprofit organization of WV parents and professionals whose goal is to support best practices while making positive changes in the state to enable West Virginia's children with Autism Spectrum Disorder to achieve their highest potential. We support a seamless, comprehensive plan for screening, early identification, and diagnosis of Autism Spectrum Disorder and access for all families to scientifically validated best outcome treatment (Early Intensive Behavior Intervention).

MAP was formed by a group of West Virginians committed to helping families recognize, understand, and successfully manage the challenges of Autism Spectrum Disorder. At the founding of MAP, it was estimated that only about 1.6% of the state's children with Autism Spectrum Disorder were receiving intensive, evidence-based services, which is why MAP is dedicated to ensuring the early detection, diagnosis, and Early Intensive Behavior Intervention of every child with Autism Spectrum Disorder in West Virginia. We work to increase access to information and resources for parents, train physicians and other diagnosticians to detect and diagnose Autism Spectrum Disorder earlier, and increase the number of professionals who are qualified to deliver evidence-based services.

In our short history, we have led successful efforts to pass Legislation that would mandate Autism Spectrum Disorder insurance coverage for young children in WV, worked with the WV Legislature's Government Organization committee to clarify oversight for Board Certified Behavior Analysts in WV, developed and implemented a program (TRAIN-WV) to help stakeholders implement autism insurance in WV, held town meetings for WV families to learn more about Autism Spectrum Disorder insurance, and provided information to families across the state interested in ABA services. We are working to expand Autism Spectrum Disorder coverage for all children in WV, and provide state-wide training for families on topics specific to Autism Spectrum Disorder, such as preparing for adolescence, wandering, and family stress. MAP is open to all parents and family members of children with Autism Spectrum Disorder and to professionals committed to supporting Early Intensive Behavior Intervention. If you are interested in attending a MAP meeting or becoming a Friend of MAP, please visit our web site or check out our Facebook page - https://www.facebook.com/pg/WVMAP/about/?ref=page_internal.

Collaborating Agency Groups

West Virginia Team Autism

West Virginia Team Autism (WVTA) is comprised of representatives from West Virginia agencies serving individuals with ASD as well as parents and others who support this population. The team began its work in 2007, bringing together representatives from all across the state to discuss relevant issues and gaps in service delivery. This collaborative group continues to meet quarterly to work together to share information, provide support, bridge gaps in services and implement progressive services with positive outcomes. The mission of West Virginia Team Autism is to build and maintain a statewide collaborative network to fully and appropriately support West Virginians with ASD and their families. One of the earlier initiatives of this group was to develop a resource guide for families to provide information on services available specific to West Virginia. This guide is the result of that initiative.

Silo Spanners

Mission Statement: *"Building capacity to effectively serve West Virginia's children who experience complex support needs."*

Vision Statement: *"Children get what they need when they need it, where they need, to reach their full potential."*

Silo Spanners, formally the Children with Co-Existing Disorders Best Practice Oversight Committee, is a re-envisioned cross-disability group dedicated towards aligning public and private entities from across West Virginia's many service systems that have historically been "siloed". Our purpose is to address the needs of children who identify with co-existing mental illness and developmental disabilities who present with complex multi-tiered support needs.

Silo Spanner's primary focus areas include: research and recommendations of best and promising practices, building and strengthening meaningful networking opportunities between service delivery systems, and developing resources to impact the overall expertise of the workforce providing day to day care to these individuals.

The Silo Spanners group welcomes motivated individuals who can add expertise, perspective, and feedback as the teams move towards developing and recommending best practice support, technical assistance, and resources to the various service systems in West Virginia. If you are interested in more information on how you can be involved, feel free to email Nikki Tennis (nikki.a.tennis@wv.gov) or Michelle Dean (michelle.c.dean@wv.gov).

DIAGNOSIS AND ASSESSMENT INFORMATION

Screening and Diagnosis for Autism Spectrum Disorder:

<http://www.cdc.gov/ncbddd/autism/screening.html>

Diagnosing Autism Spectrum Disorder (ASD) can be difficult, since there is no medical test, like a blood test, to diagnose the disorders. Doctors look at the child's behavior and development to make a diagnosis.

ASD can sometimes be detected at 18 months or younger. By age 2, a diagnosis by an experienced professional can be considered very reliable. ^[1] However, many children do not receive a final diagnosis until much older. This delay means that children with an ASD might not get the help they need.

Diagnosing an ASD takes two steps:

1. Developmental Screening

Developmental screening is a short test to tell if children are learning basic skills when they should, or if they might have delays. During developmental screening the doctor might ask the parent some questions or talk and play with the child during an exam to see how she learns, speaks, behaves, and moves. A delay in any of these areas could be a sign of a problem.

All children should be screened for developmental delays and disabilities during regular well-child doctor visits at:

- 9 months
- 18 months
- 24 or 30 months
- Additional screening might be needed if a child is at high risk for developmental problems due to preterm birth, low birth weight or other reasons.

In addition, all children should be screened specifically for ASD during regular well-child doctor visits at:

- 18 months
- 24 months
- Additional screening might be needed if a child is at high risk for ASD (e.g., having a sister, brother or other family member with an ASD) or if behaviors sometimes associated with ASD are present

It is important for doctors to screen all children for developmental delays, but especially to monitor those who are at a higher risk for developmental problems due to preterm birth, low birth weight, or having a brother or sister with an ASD.

If your child's doctor does not routinely check your child with this type of developmental screening test, ask that it be done.

If the doctor sees any signs of a problem, a comprehensive diagnostic evaluation is needed.

2. Comprehensive Diagnostic Evaluation

The second step of diagnosis is a comprehensive evaluation. This thorough review may include looking at the child's behavior and development and interviewing the parents. It may also include a hearing and vision screening, genetic testing, neurological testing, and other medical testing.

In some cases, the primary care doctor might choose to refer the child and family to a specialist for further assessment and diagnosis. Specialists who can do this type of evaluation include:

- Developmental Pediatricians (doctors who have special training in child development and children with special needs)
- Child Neurologists (doctors who work on the brain, spine, and nerves)
- Child Psychologists or Psychiatrists (doctors who know about the human mind)

For More Information on Screening and Diagnosis Visit
Learn The Signs/Act Early - www.cdc.gov/ncbddd/autism/screening.html

AUTISM SPECTRUM DISORDER RESOURCES SPECIFIC TO AGE GROUPS

Early Intervention

WV Birth to Three - <http://www.wvdhhr.org/birth23/>

WV Birth to Three directs the coordination of the statewide system of early intervention services for families with children age birth to three that have developmental delays.

Education

Office of Special Education - <http://wvde.state.wv.us/osp/>

The West Virginia Department of Education, Office of Special Education supports County Boards of Education in educating all students, aged three to 21. They have developed a guidance document for educating students with Autism Spectrum Disorder you might find helpful. You can locate this document at http://wvde.state.wv.us/osp/autisum_guidance_1-6-12.pdf.

Adults

- WV Bureau For Behavioral Health Services And Health Facilities - <http://www.dhhr.wv.gov/bhhf/Pages/default.aspx>
 - Other Behavioral Health Service Providers:
 - Appalachian Community Health Center – <http://achcinc.org>
 - The Arc of the Three Rivers – website under construction – 304-344-3403
 - Autism Services Center – <http://autismservicescenter.org>
 - EastRidge Health Systems- <http://eastridgehealthsystems.org>
 - FMRS Health Systems - <http://fmrs.org>
 - HealthWays - <http://healthwaysinc.com>
 - Logan Mingo Area Mental Health - (304) 792-7130
 - Northwood Health Systems - <http://www.northwoodhealth.com>
 - The Potomac Center - <http://potomaccenter.com>
 - Potomac Highlands Guild - <http://thephg.org>
 - Pretera Center for Mental Health Services - <http://pretera.org>
 - Seneca Health Services - <http://shsinc.org>
 - Southern Highlands Community Mental Health Center - <http://shcmhc.com>
 - United Summit Center - <http://uscwv.org>
 - Valley Health Care - <http://valleyhealthcare.org>
 - Westbrook Health Service - <http://www.westbrookhealth.com>
- College Program For Students With Autism Spectrum Disorder - <http://www.marshall.edu/collegeprogram/>
- Goodwill - <http://www.goodwill.org/>
- Housing And Urban Development (HUD) - <http://www.hud.gov/>
- Intellectual Developmental Disabilities Waiver - <http://www.dhhr.wv.gov/bms/Programs/WaiverPrograms/IDDW/Pages/default.aspx>
- Medicaid - <http://www.dhhr.wv.gov/bms/Pages/default.aspx>
- Oar/Organization For Autism Research - <http://www.researchautism.org/resources>
- Social Security - <http://www.ssa.gov/>
- Vivient Monitoring Systems - <http://www.vivint.com/en/>
- West Virginia Division Of Rehabilitation Services - <http://www.wvdrs.org/>
- WV Developmental Disabilities Council - <http://www.ddc.wv.gov/RESOURCES/Pages/default.aspx>

Additional Resources

The College Support Program for Students with ASD- <http://www.marshall.edu/collegeprogram/>

The College Program for Students with ASD was developed in 2002, by the West Virginia Autism Training Center at Marshall University.

The fee-based program exists to offer appropriate academic, social and independent living skill supports to individuals with Autism Spectrum Disorder, so that they may have a successful college experience and learn skills necessary to enter a competitive workforce.

Online Asperger Syndrome Information and Support - <http://www.aspergersyndrome.org/>

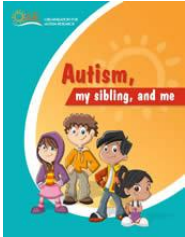
The Online Asperger Syndrome Information and Support (OASIS) center has joined with MAAP Services for Autism Spectrum Disorder and Asperger Syndrome to create a single resource for families, individuals, and medical professionals who deal with the challenges of Asperger Syndrome, Autism Spectrum Disorder, and Pervasive Developmental Disorder/ Not Otherwise Specified (PDD/NOS)

ADDRESSING SIBLING ISSUES

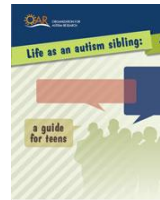
*Siblings need support too.
There are many resources that address sibling issues.
A few are provided below.*

A Siblings Guide to Autism/Autism Speaks Family Support Tool Kit (2011) www.autismspeaks.org. Go to the website and submit your email to download the Sibling Tool Kit (No cost)

OARS (Organization for Autism Research) “Autism Sibling Support” Initiative offers guidance for young children, teenagers and parents on how to productively address the ups and downs that may arise for individuals who have a brother or sister with autism. www.researchautism.org/family Two guide books are offered:



Autism, My Sibling and Me
workbook for siblings
between the ages of 5 and
10.



Life as an Autism Sibling: A Guide for Teens is a handbook for teenage sibling that offers guidance on how to productively address feelings and challenges that may arise as an autism sibling

Both booklets are offered at no cost by sending an email to programs@researchautism.org

Additional Websites:

- <http://www.autism-society.org/living-with-autism/family-issues/siblings/>
- <http://theautismblog.seattlechildrens.org/siblings-and-autism>
- http://www.autismspeaks.org/sites/default/files/a_siblings_guide_to_autism.pdf

EDUCATIONAL APPROACHES TO AUTISM SPECTRUM DISORDER

There are many different opinions about how best to help children with Autism Spectrum Disorder. There are two general approaches to instruction: those based on [Applied Behavior Analysis \(ABA\)](#) and those that follow a [Developmental Approach](#).

In general, ABA approaches are more structured in terms of environmental arrangements and skill expectations. In ABA approaches, the adult will systematically encourage certain responses from the child and then respond in planned ways designed to either increase or decrease certain behaviors. Behavioral approaches also carefully measure progress and modify strategies based on the data collected (see the quality indicators of ABA programs on page 85). Developmental approaches are often more spontaneous in the way that adults will respond to the child, and the child's behavior. For children functioning at early stages of development, emphasis is put on encouraging the child to develop his own ideas and to engage in social interactions in reciprocal ways. In many of these approaches, the focus is on thinking about the 'whole child' including the child's regulatory and sensory challenges.

There are many educational models and strategies available to families and schools today. Families are encouraged to look at all of the approaches and, along with your child's teacher or other professionals, decide on what strategy, or combination of strategies best fit your child and family. While there are no conclusive studies showing that one approach is better than another, we do know that the most affective approaches are intensive and implemented as early as possible. Models that have been researched include, but are not limited to:

- Discrete Trial Instruction
- Developmental Intervention
- Activity Based (Naturalistic) Instruction
- Pivotal Response Training
- TEACCH Method

It is important that families and educators identify specific skills that they would like to work on, and continually monitor instruction to see if progress is being made. If progress is not being made, it is critical that the team seeks to understand why this may be, and how instruction might change to better address the child's needs.

Following are examples of the first three approaches listed above (discrete trial instruction; activity-based instruction; developmental intervention) to demonstrate that the same skill can be taught in a variety of ways. The skill that is exemplified below is "imitating an adult."

- **Discrete Trial Instruction (DTI)** - The "Discrete Trial" strategy is a frequently used intervention based on Applied Behavior Analysis (ABA). Here, specific skills are taught to a child in a one-on-one structured learning setting. Usually, a child is given a specific instruction by his teacher, and the child responds. The child is either rewarded for a correct response, or provided with a correction for an incorrect response.
- **Developmental Intervention** - In this approach, instead of directing the child to do something ("Jake, do this"), the teacher or therapist sets up a situation that encourages the child to initiate a desired behavior. Then, the focus of the intervention is to build on this initiation to develop further engagement, thinking, and communication.
- **Activity-Based (Naturalistic) Instruction**- Activity-based instruction combines aspects of Discrete Trial Instruction and Developmental Intervention strategies described above. Here, the child is systematically taught a skill during ordinary activities throughout his school day or at home, making sure that many opportunities are given to repeat and learn the skill.

The three examples described above are just a few of the many types of interventions that have been

used to successfully teach young children with Autism Spectrum Disorder. The important thing to remember is that, whatever approach is used, you should feel comfortable with it. To read about real life stories teaching skills using these different methods visit <http://www.pbs.org/parents/inclusivecommunities/autism4.html>.

The above information has been taken from <http://www.pbs.org/parents/inclusivecommunities/Autism Spectrum Disorder4.html>

SOCIAL LANGUAGE USE (PRAGMATICS)

Information taken from the American Speech-Language Hearing Association www.asha.org

Social Language is a frequent problem associated with Autism Spectrum Disorder. Below is some information about social language and the tools used during the therapy.

An individual may say words clearly and use long, complex sentences with correct grammar, but still have a communication problem – if he or she has not mastered the rules for social language known as pragmatics.

Pragmatics involves three major communications skills:

1. **Using language for different purposes such as**
 - Greeting
 - Informing
 - Demanding
 - Promising
 - Requesting

2. **Changing language according to the needs of a listener or situation such as**
 - Talking differently to a young child than to an adult
 - Giving background information to an unfamiliar listener
 - Speaking differently in a classroom than on a playground

3. **Following rules for conversation and storytelling, such as**
 - Taking turns in a conversation
 - Introducing topics of conversation
 - Staying on topic
 - Rephrasing when misunderstood
 - How to use verbal and non-verbal cues
 - How close to stand to someone when speaking
 - How to use facial expression and eye contact according to the conversation

RESOURCES RELATED TO APPLIED BEHAVIOR ANALYSIS PROGRAMS

Quality Indicators of an ABA Program

When a parent decides to seek ABA therapy for their child, it is important to make informed decisions about providers and the programs they offer. The 30-point criterion listed below is compiled from multiple sources, each of which focuses on determining components necessary to make effective, behavioral change in individuals with neurological disabilities, such as Autism Spectrum Disorder. The following are offered as:

30 Indicators of a Quality ABA Program:

1. Begins early, before age 3
2. Leading to Independence - is Independence fostered?
3. Working closely with families - include extended family and caregivers
4. Provides a structured environment
5. Plans for generalization to natural environments
6. Hierarchy of instructional priorities - skills taught include mastery criteria

7. Curriculum includes: attending to elements in the environment, imitation skills, understanding and using language, playing appropriately with toys, and interacting socially.
8. Plans and prioritizes maintenance of mastered skills
9. Individualized programming
10. High rates of Active Student Responding (ASR)
11. Considers student motivation
12. Progress is monitored
13. Changes made are based on measures of progress
14. Conduct functional assessment/analysis of behavior - aberrant and academic
15. Immediate feedback is given to student
16. Predictability and routine are established
17. Use of accurate, immediate models and modeling, errorless strategies
18. Measures of baseline data are taken
19. Ongoing supervision is provided by a competent, trained individual
20. Low student to staff ratios (not too many students per staff)
21. Behavior plans, teaching sequences and programs are written
22. Monitoring of treatment integrity (the degree to which a program is implemented as intended)
23. Plans for transitions are considered and are in place
24. Uses empirically-validated teaching methods
25. Interdisciplinary; the team collaborates w/other disciplines, including medical staff as appropriate
26. Intensive teaching is available - increase in number of hours traditionally provided, if recommended
27. Treatment acceptability; program includes measures of social validity
28. Use of self-management procedures, when appropriate
29. Measures of fluency (accuracy/speed=fluency)
30. Teaches generative/pivotal skills

The indicators listed above are suggestions from information referenced by the following resources (click on the link to access each source):

- Baer, D., Taylor, M., Taylor, B. (2005). *Focus on behavior analysis in education*. Chapters 1 and 2. http://www.amazon.com/Focus-Behavior-Analysis-Education-Opportunities/dp/0131113399/ref=sr_1_1?ie=UTF8&qid=1318812547&sr=8-1
- Maine Administrators of Services for Children with Disabilities (2000). Report of the Autism Spectrum Disorder task force. Retrieved from <http://www.madsec.org/LinkClick.aspx?fileticket=YmikqkW4tFk%3D&tabid=81>.
- National Institutes for Health (1999). Mental health: A report of the surgeon general. Chapter 3. Retrieved from <http://profiles.nlm.nih.gov/ps/retrieve/ResourceMetadata/NNBBHS>.
- New York Department of Health (1999). Clinical practice guideline: Report of the recommendations. Retrieved from http://www.health.ny.gov/community/infants_children/early_intervention/disorders/autism_spectrum_disorder/ch4_pt2.htm.
- For more information... Los Angeles Families for Effective Autism Spectrum Disorder Treatment – Components of a Quality ABA Program - http://www.lafeat.org/web/aba_components/

To find a Board Certified Behavior Analyst (BCBA) in your area visit <http://www.bacb.com/>. The list of BCBA's is under "Find/Contact Certificants" on the left hand side of the home page. Select "WV" in the "State(US Only) box. A list of behavior analysts certified in WV will be shown. This section is updated regularly as new professionals become certified.

A BCBA is an individual who studies human behavior and attempts to improve it. They approach these activities through the use of Applied Behavior Analysis (ABA) programs. ABA programs – carried out most often in a Discrete Trial Instruction approach – are delivered in a variety of environments, including clinic-based, home-based, and school-based. Please contact a BCBA in your region, or the Director of Special Education in your county, to find out what options exist for you.

Resources Related To Positive Behavioral Support

Positive Behavior Support (PBS) - <http://challengingbehavior.fmhi.usf.edu/explore/pbs/pbs.htm> Positive Behavior Support (PBS) is a framework of behavioral assessment and intervention that is explicitly designed to promote improvements in an individual or family's quality of life. Grounded in the individual or family's goals and values, PBS uses functional assessments to identify the underlying purpose of a specific behavior, and then uses a package of interventions to prevent future occurrences of problem behaviors by making it less relevant and effective than a more age- and socially-appropriate skill taught as its replacement.

WV Association of Positive Behavior Support Network – <http://www.wvapbs.blogspot.com/> Or <https://www.facebook.com/WVAPBS> The WV APBS Network's web site is home to information, resources, services, and links pertaining to Positive Behavior Support (PBS) in West Virginia and around the country. Here you will find trainings and providers for PBS services and learn about the methods used by PBS to understand and managing challenging behavior.

Additional Websites:

- Association for Positive Behavior Support (APBS) - <http://www.apbs.org/>
- Positive Behavioral Intervention & Supports - <http://www.pbis.org/>
- Florida's Positive Behavior Support (PBS) Project - <http://flpbs.fmhi.usf.edu/>

Definitions

Definitions are, in part, adapted from Autism Speaks' 100 Day tool Kit; Autism Delaware- delautism.org; ASHA; APBS; Academy of Nutrition and Dietetics; and American Occupational Therapy Association

A

Absence Seizure, see **Seizures**.

Adaptive Behavior refers to the ability to adjust to new experiences, interact with new people, and participate in new activities and experiences.

Adaptive Equipment may refer to furniture and other positioning support that can be used to help an individual maintain comfortable and appropriate posture and functioning when sitting, standing or moving.

Americans with Disabilities Act (ADA) is the US law that ensures the civil rights of persons with disabilities regarding employment, public services, and accommodations.

Angelman Syndrome is a genetic disorder causing developmental delays and neurological problems, often accompanied by seizures. Children often display hyperactivity, small head size, sleep disorders and movement and balance disorders.

Anticonvulsant is a type of drug used to prevent or stop seizures or convulsions; also called **antiepileptic**.

Anxiety Disorder is a disorder that affects an estimated 30% of individuals with autism and includes social phobia, separation anxiety, panic disorder and specific phobias. An individual who lives with significant anxiety may experience strong internal sensations of tension such as a racing heart, muscular tensions and stomachache.

Applied Behavior Analysis (ABA) is a style of teaching using series of trials to shape desired behavior or response. Skills are broken into small components and taught to child through a system of reinforcement.

Articulation refers to the ability to produce speech sounds

Asperger's Disorder is a developmental disorder on the autism spectrum defined by impairments in communication, social development, and repetitive interests and behaviors, without a significant delay in language and cognitive development. *The diagnosis is no longer used in DSM-5, but DSM-5 indicates that individuals with a "well-established diagnosis" of these conditions "should be given the diagnosis of Autism Spectrum Disorder."*

Assistive and Augmentative Communications (AAC) are additional materials, supports, equipment, and electronic devices that help people communicate when their spoken language is not sufficient for their needs.

Assistive Technology: Electronic – as well as non-electronic – materials, equipment, and devices designed to help people with disabilities play, learn, communicate, move around, and carry out activities of daily living at home, at school, and in the community.

Attention Deficit Hyperactivity Disorder (ADHD) is a disorder that affects approximately 1 in 5 children with autism. Symptoms include chronic problems with inattention, impulsivity and hyperactivity.

Audiologist is a professional who diagnoses and treats individuals with hearing loss or balance problems.

Auditory Integration Training, or sound therapy, is used to treat children with difficulties in auditory processing or sound sensitivity and involves the individual listening to electronically modified music through headphones during multiple sessions.

Augmentative Communication refers to any method of communicating without speech, such as by signs, gestures, picture boards, or electronic or non-electronic devices. These methods can help individuals who are unable to use speech or who need to supplement their speech to communicate effectively.

Autism Diagnostic Observation Schedule (ADOS) is an assessment commonly used for diagnosing ASD and, along with information from parents, may be incorporated into a child's evaluation.

B

Baseline refers to level of function by an individual before instruction and/or intervention is introduced.

Behavior Intervention Plan is a written document that becomes part of the IEP and which identifies problem behaviors; sets goals for decreasing unwanted behaviors and increasing desired behaviors; and outlines interventions to use when specific behaviors occur.

C

Casein is protein found in milk, used in forming the basis of cheese and as a food additive.

Childhood Autism Rating Scale (CARS) is a scale developed at TEACCH (Treatment and Education of Autistic and Related Communication-handicapped Children) for use in the diagnosing of an Autism Spectrum Disorder, where a child is rated in fifteen areas of ability.

Childhood Disintegrative Disorder is a disorder in which development begins normally in all areas, physical and mental. At some point between 2 and 10 years of age, the child loses previously developed skills. The child may lose social and language skills and other functions, including bowel and bladder control. *The diagnosis is no longer used in DSM-5, but DSM-5 indicates that individuals with a "well-established diagnosis" of these conditions "should be given the diagnosis of Autism Spectrum Disorder."*

Cognitive Skills are any mental skills that are used in the process of acquiring knowledge; these skills include reasoning, perception and judgment.

Compulsions are deliberate repetitive behaviors that follow specific rules, such as pertaining to cleaning, checking, or counting. In young children, restricted patterns of interest may be early sign of compulsions.

Cue refers to a physical or verbal/vocal gesture that prompts a person to speak, perform an activity or behave in a particular way.

D

Declarative Language is used to communicate what the mind is producing. It is what is most common in conversation, whereas **Imperative Language** is used to ask questions, make commands or give instructions.

Developmental Disorder refers to several disorders that affect typical development. May affect single area of development (specific developmental disorders) or several (pervasive developmental disorders).

Developmental Milestone is the acquisition of a skill that is associated with a certain age, e.g. sitting up; saying first words.

Dietitian is an expert in **dietetics**; that is human nutrition and the regulation of diet. A dietitian alters their patient's nutrition based upon their medical condition and individual needs. Dietitians are regulated healthcare professionals licensed to assess, diagnose, and treat nutritional problems.

Dyspraxia refers to the brain's inability to plan muscle movements and carry them out.

E

Early Intervention (EI) is a state-funded program designed to identify and treat developmental problems or other disabilities as early as possible. Eligibility for EI is from birth to three years of age. In WV the early intervention program is known as **WV Birth to Three**.

Early Start Denver Model (ESDM) is a comprehensive behavioral early intervention approach for children with autism, ages 12 to 48 months, that uses a developmental curriculum that defines the skills to be taught at any given time and a set of teaching procedures used to deliver this content.

Echolalia is repeating words or phrases heard previously, either immediately after hearing word or phrase or much later. **Delayed echolalia** occurs days or weeks later. **Functional echolalia** is using a quoted phrase in a way that has shared meaning, for example, saying “carry you” to ask to be carried.

Elopement refers to the wandering, or running away from an area of supervision.

Epilepsy (seizure disorder) is a pattern of repeated seizures, with causes that may include head injury, brain tumor, lead poisoning, genetic and infectious illnesses. Cause is unknown in 50% of cases.

Executive Function refers to the ability to plan, organize and follow through, as well as the ability to inhibit actions, delay responses, make appropriate choices and shift attention. Individuals with ASD, learning disabilities and other neurological conditions often have deficits in executive function, which is important to the attainment of goals.

Expressive Labeling is the communication of a name for an object or person (see **expressive language**).

Expressive Language is communication of intentions, desires, or ideas to others, through speech or printed words and includes gestures, signing, communication board and other forms of expression.

Extended School Year (ESY) services are provided during breaks from school, such as during summer vacation, for students who experience substantial regression in skills during school vacations.

F

Fine motor skills involve the use of one’s hands for manipulating objects and performing activities.

Free Appropriate Public Education (FAPE) means that education must be provided to all children ages three to twenty-one at public expense.

Floortime is a developmental intervention for children with autism that involves meeting a child at his current developmental level and building upon a particular set of strengths.

Fragile X Syndrome is a genetic disorder that shares many of the characteristics of autism such as developmental problems including learning disabilities and cognitive impairment. Individuals may be tested for Fragile X.

Functional Behavioral Assessment is a process based largely on observation in which problem behaviors are addressed and analyzed. Causes and functions of the behavior are identified. A behavior intervention plan (BIP) or positive behavior support plan (PBSP) based on a specific, individualized profile is then developed and, ideally, implemented across settings in order to minimize or stop inappropriate behaviors and replace functionally equivalent replacement behaviors.

G

Geneticist refers to a medical doctor who specializes in genetic disorders.

Genes are the unit in the chromosome that contain the blueprint for the transmission of inherited characteristics.

Gestures are hand and head movements, used to signal to someone else, such as a give, reach, wave, point or head shake. They convey information or express emotions without the use of words.

Global Developmental Delay is diagnosis in children younger than 5, characterized by delay in two or more developmental domains, sometimes associated with Intellectual Disability.

Gross Motor Skills involves the use of one's large muscles to move, such as walking, running, hopping and jumping.

Gluten is a protein present in wheat, rye and barley.

Grand mal seizure, see **Seizures**.

H

Hand-Over-Hand Guidance refers to physically guiding an individual through the movements involved in a fine motor task. Helping someone to grasp a spoon and bring it to his or her mouth is an example of hand-over-hand guidance.

Hyperlexia is the ability to read at an early age. To be hyperlexic, a child does not need to understand what he or she is reading.

Hyperresponsiveness, hypersensitivity, see **Sensory Defensiveness**

Hyporesponsiveness and/or **hyposensitivity**, is abnormal insensitivity to sensory input. Could be exhibited by a child who appears to be deaf, whose hearing is normal, is under reactive to sensory input, may have a high tolerance to pain, may be clumsy, sensation seeking and may act aggressively.

Hypertonia is characterized by increased tension or stiffness in the muscles.

Hypotonia is characterized by decreased tension or floppiness in the muscles.

I

The IDD Waiver (IDDW) Program is West Virginia's home and community-based services program for individuals with intellectual and/or developmental disabilities. It is administered by BMS pursuant to a Medicaid waiver option approved by the Centers for Medicare and Medicaid Services (CMS), the federal agency responsible for the IDDW Program. The IDDW Program is a program that reimburses for services to instruct, train, support, supervise, and assist individuals who have intellectual and/or developmental disabilities in achieving the highest level of independence and self-sufficiency possible. The IDDW Program provides services based on a person's annual functional assessment and assigned individualized budget in natural settings, homes, and communities where the person resides, works, and shops.

Incidental Teaching teaches a new skill while in their home or community, in natural context or "in the moment," to help make sense of what they learn during formal instruction and generalize new skills.

Incontinence is characterized by a lack of bladder or bowel control.

Individual Family Service Plan (IFSP) is developed by a multidisciplinary team including family as primary participant. Describes infant or toddler's level of development in all areas; family's resources, priorities and concerns, outcomes to be achieved and the frequency of services, intensity and method of delivery. Must state natural environments in which services will occur.

Individualized Education Plan (IEP) identifies student's specific learning expectations, how school will address them with appropriate services and methods to review progress. For students 14 and older, must contain plan to

transition to postsecondary education or the workplace or to help the student live as independently as possible in the community.

Individualized Program Plan (IPP) Central to the services that a person receives through the IDDW Program is the person's IPP. Developing the IPP is the process by which the person is assisted by the Interdisciplinary Team which consists of their legal representative (when applicable), their advocate (when applicable) other natural supports the person who is receiving services chooses to invite, as well as attendees required by the IDDW Program policy manual. This team meets to decide what needs to be done, by whom, when and how and to document the decisions made by this planning team. The content of the IPP must be guided by the person's needs, wishes, desires, and goals but based upon assessed needs and each person's individualized budget.

Individuals with Disabilities Education Act (IDEA) is the US law mandating the "Free and Public Education" of all persons with disabilities between ages 3 and 21.

Inclusion involves educating all children in general education classrooms, regardless of degree or severity of disability. Effective inclusion takes place with planned system of training and supports; involves collaboration of multidisciplinary team including regular and special educators.

Intellectual Disability is a term used when there are limits to a person's ability to learn at an expected level and function in daily life.

J

Joint Attention is the process of sharing one's experience of observing an object or event, by following gaze or pointing gestures. Critical for social development, language acquisition, cognitive development. Impairment in joint attention is a core deficit of ASD.

K

L

Least Restrictive Environment (LRE) is setting that least restricts opportunities for child with disabilities to be with peers without disabilities. The law mandates that every child with a disability be educated in a Least Restrictive Environment.

M

Mainstreaming is where students are expected to participate in existing regular education classes, whereas in an inclusive program, classes are designed for all students. May be gradual, partial or part-time process (e.g., student may attend separate classes within regular school or participate in regular gym and lunch only).

Modified Checklist of Autism in Toddlers (MCHAT) is a screening tool for identifying young children who may be referred to specialist for further evaluation and possible Autism Spectrum Disorder diagnosis.

Motor Deficits are physical skills that a person cannot perform or has difficulty performing.

Motor Function (or motor skills) is the ability to move and control movements.

Motor Planning refers to the ability to think through and physically carry out a task.

Motor Skill is the learned ability to perform movements, such as holding the body in an upright position to sit, using the hands to manipulate small items, scooping food onto a spoon and bringing the spoon to the mouth, and moving the lips and tongue to articulate different sounds.

N

Neurologist refers to a doctor specializing in medical problems associated with the nervous system, specifically the brain and spinal cord.

Neuro-motor describes a process involving both the nervous system and muscles.

Neurotypical is a term used within the autism community to describe individuals not diagnosed with an Autism Spectrum Disorder.

Nonverbal Behaviors are things people do to convey information or express emotions without words, including eye gaze, facial expressions, body postures and gestures.

O

Obsessions are persistent and intrusive repetitive thoughts. Preoccupations with specific kinds of objects or actions may be an early sign of obsessions.

Occupational Therapy assists development of fine motor skills that aid in daily living. May focus on sensory issues, coordination of movement, balance and self-help skills such as dressing, eating with a fork, grooming, etc. May address visual perception and hand-eye coordination.

Occupational Therapist helps minimize impact of disability on independence in daily living by adapting child's environment and teaching sub-skills of the missing developmental components.

Operant Conditioning is the modification of behavior through positive and/or negative reinforcement.

P

Parallel Play is a developmental psychology concept in which toddlers (ages 2-3 years) play alongside each other, in similar activities, without obvious communication or interaction. Children younger than that tend to play by themselves (solitary play). Older children (preschool age) interact with each other more during group play.

Performance I.Q. is the intelligence test score derived from various non-verbal tests, such as visual-spatial activities and object assembly.

Perseveration is repetitive movement or speech or sticking to one idea or task, that has a compulsive quality to it.

Pervasive Developmental Disorders (PDD), as described in the previous DSM-IV TR is a group of conditions involving delays in development of many basic skills, including ability to socialize with others, to communicate and use imagination. Included Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, Rett Syndrome, and Pervasive Developmental Disorder - Not Otherwise Specified. *The diagnostic criteria/diagnoses have changed with the implementation of the DSM5.*

Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) a category of PDD referring to children having significant problems with communication and play and some difficulty interacting with others, but are too social for diagnosis of autism. *The diagnosis is no longer used in DSM5, but DSM5 indicates that individuals with a "well-established diagnosis" of these conditions "should be given the diagnosis of autism spectrum disorder."*

Petit Mal Seizure, see **Seizures**.

Physical Therapy uses specially designed exercises and equipment to help patients regain or improve their physical abilities.

Physical Therapist designs and implements physical therapy programs and may work within a hospital or clinic, in a school or as an independent practitioner.

Pica is persistent eating or mouthing of non-nutritive substances for at least 1 month when behavior is developmentally inappropriate (older than 18-24 months). Substances may include items such as clay, dirt, sand, stones, pebbles, hair, feces, lead, laundry starch, wood, plastic and more.

Picture Exchange Communication System (PECS) is an alternative communication system using picture symbols taught in phases starting with simple exchange of symbol for desired item. Individuals learn to use picture symbols to construct complete sentences, initiate communication and answer questions.

Pivotal Response Treatment (PRT) is a therapeutic teaching method using incidental teaching opportunities to target and modify key behaviors related to communication, behavior, and social skills.

Positive Behavior Support is a set of processes that combine information from social, behavioral, and biomedical science and applies this information at the individual and/or systems level to reduce behavioral challenges and improve quality of life. Both systems-wide and individualized interventions used in PBS are empirically documented and can be used by a wide range of support providers.

Pragmatics are social rules for using functional spoken language in a meaningful context or conversation. Challenges in pragmatics are a common feature of spoken language difficulties in children with ASD.

Prevalence is the current number of people in a given population who have a specific diagnosis at a specified point in time. As of May 2014, the U.S. Centers for Disease Control and Prevention estimated autism prevalence as 1 in 68 children, including 1 in 42 boys and 1 in 189 girls.

Prompt refers to input that encourages an individual to perform a movement or activity. A prompt may be verbal, gestural or physical.

Prompts for Restructuring Oral Muscular Phonetic Targets (PROMPT) is an approach used in speech-language therapy that manually guides an individual's jaw, tongue and lips through a targeted word, phrase or sentence to develop motor control and proper oral muscular movements, while eliminating unnecessary muscle movements such as jaw sliding.

Proprioception is the receiving of stimuli originating in muscles, tendons, and other internal tissues.

Prosody is the rhythm and melody of spoken language expressed through rate, pitch, stress, inflection or intonation. Some children with ASD have unusual intonation (flat, monotonous, stiff or "sing songy" without emphasis on the important words).

Psychiatrist is a medical doctor specializing in prevention, diagnosis, and treatment of mental illness or disorders who has received additional training and completed a supervised residency in specialty. May have additional training in specialty, such as child psychiatry or neuropsychiatry and can prescribe medication (which psychologists in WV cannot do).

Psychologist is a professional who diagnoses and treats diseases or disorders of the brain, emotional disturbance, and behavior problems. May have a master's degree (M.A.) or doctorate (Ph.D., Psy.D.) in psychology. May have other qualifications, including Board Certification and/or additional training in a specific type of therapy, including Applied Behavioral Analysis.

Q

R

Receptive Labeling, see *receptive language*.

Receptive Language is the ability to comprehend words and sentences and begins as early as birth and increases with each stage in development. By 12 months of age, a child begins to understand words and responds to his or

her name and may respond to familiar words in context. By 18 to 20 months, a child identifies familiar people by looking when named (e.g., Where's mommy?), gives familiar objects when named (e.g., Where's the ball?) and points to a few body parts (e.g., Where's your nose?). These skills commonly emerge slightly ahead of expressive language skills. Reinforcement or reinforcer, is any object or event following a response, increasing or maintaining the rate of responding. Positive reinforcer may be produced by or added after a response.

Regression refers to the loss of skills that have already been learned.

Reinforcement is a behavior modification technique used to increase the likelihood of a desired response or behavior. **Positive reinforcement** is accomplished by immediately strengthening or rewarding a desirable behavior. The reward can be a social reinforcer, such as praise or a hug, or it can be material, such as a sticker or other desired item. One form of **negative reinforcement** is to withdraw a privilege.

Relationship Development Intervention (RDI) is a therapeutic teaching method based on building intelligence competencies of social connection – such as referencing, emotion sharing, coregulation and experience sharing – that normally develop in infancy and early childhood.

Respite Care is temporary, short-term care provided to individuals with disabilities, delivered in the home for a few short hours or in an alternate licensed setting for an extended period of time. Respite care allows caregivers to take a break in order to relieve and prevent stress and fatigue.

Rett Syndrome is a very rare disorder in which patients have symptoms associated with PDD along with problems with physical development. They generally lose many motor or movement skills – such as walking and use of hands – and develop poor coordination. The condition has been linked to a defect on the X chromosome and as a result, almost always affects girls.

S

Savant Syndrome is a condition in which a person with a developmental disability demonstrates profound and prodigious capacities or abilities far in excess of what would be considered normal. People with savant syndrome may have neurodevelopmental disorders, notably autism spectrum disorders, or brain injuries. The most dramatic examples of savant syndrome occur in individuals who score very low on IQ tests, while demonstrating exceptional skills or brilliance in specific areas, such as rapid calculation, art, memory, or musical ability. *Although termed a syndrome, it is not recognized as a mental disorder nor as part of a mental disorder in medical manuals such as the ICD-10 or the DSM-5.*

Section 504 of the Rehabilitation Act refers to a civil rights statute designed to eliminate discrimination on the basis of disability in any program or activity receiving federal financial assistance. Some individuals who do not qualify for services under IDEA may receive services and/or accommodations under Section 504.

Seizure refers to uncontrolled electrical activity in the brain, which may produce a physical convulsion, minor physical signs, thought disturbances or a combination of symptoms.

Seizure: Absence Seizure takes the form of a staring spell as the person suddenly seems “absent” and has a brief loss of awareness. May be accompanied by blinking or mouth twitching. Absence seizures have very characteristic appearance on EEG. Also called a petit mal seizure. **Atonic Seizure**, is a seizure marked by the person losing muscle tone and strength and unless supported, falls down. Atonic means lack of muscle tone and strength. **Subclinical Seizures** (Electrographic Seizures) are visible on the EEG, but the patient does not exhibit clinical symptoms. Electroencephalography often detects subclinical seizures during sleep. **Tonic Clonic Seizures** involves two phases – tonic phase when body becomes rigid and clonic phase of uncontrolled jerking. May be preceded by aura and is often followed by headache, confusion and sleep. May last for seconds or continue for several minutes.

Self-help skills are daily living skills such as self-feeding, dressing, bathing, and other tasks that are necessary to maintain health and well-being.

Self-injurious Behaviors (SIB) are maladaptive behaviors that are harmful to oneself, such as hitting oneself with hands or other body parts, head-banging, biting oneself, picking at skin or sores, or frantically scratching or rubbing oneself repeatedly to the point of bruising or other harm.

Self-Regulation and **self-control** are related but not the same. *Self-regulation* refers to both conscious and unconscious processes that have an impact on self-control, but regulatory activities take place more or less constantly to allow us to participate in society, work and family life. *Self-control* is a conscious activity.

Sensory Defensiveness is a tendency, outside the norm, to react negatively or with alarm to sensory input which is generally considered harmless or non-irritating to others. Also called hypersensitivity.

Sensory Input, see *sensory stimuli*.

Sensory Integration is the way the brain processes sensory stimulation or sensation from the body and then translates that information into specific, planned, coordinated motor activity.

Sensory Integration Dysfunction a neurological disorder causing difficulties processing information from the five classic senses (vision, hearing, touch, smell and taste), sense of movement (vestibular system) and positional sense (proprioception). Sensory information is sensed normally, but perceived abnormally. May be a disorder on its own or with other neurological conditions.

Sensory Integration Therapy is used to improve ability to use incoming sensory information appropriately and encourage tolerance of a variety of sensory inputs.

Sensory Stimulus Agent, action or condition, internal (e.g., heart rate, temperature) or external (e.g., sights, sounds, tastes, smells, touch and balance) that elicits physiological or psychological response. Response depends on ability to regulate and understand stimuli and adjust emotions to demands of surroundings.

Sleep Hygiene a set of practices, habits and environmental factors critically important for sound sleep, such as minimizing noise, light and temperature extremes and avoiding naps and caffeine.

Social Communication Disorder (SCD) is a new diagnostic category established in the DSM-5 that applies to individuals who have deficits in the social use of language, but do not have the restricted interests or repetitive behavior you see in those with autism spectrum disorders.

Social Communication/Emotional Regulation/Transactional Support (SCERTS) is an educational model of treatment that differs notably from the focus of "traditional" ABA by promoting child-initiated communication in everyday activities.

Social Reciprocity is back-and-forth flow of social interaction. How behavior of one person influences and is influenced by behavior of another and vice versa.

Social Stories, developed by Carol Gray, are simple stories that describe social events and situations that are difficult for a child with a PDD to understand. For example, a social story might be written about birthday parties if the child appears to have a difficult time understanding what is expected of him or how he is supposed to behave at a birthday party.

Social Worker is a trained specialist in the social, emotional, and financial needs of families and patients. Social workers often help families and patients obtain the services they have been prescribed.

Special Education is specially designed instruction, at no cost to families, to meet unique needs of child with disability, including instruction conducted in the classroom, in the home, in hospitals and institutions and in other settings and instruction in physical education.

Specific Learning Disability (SLD) is a developmental disorder involving difficulties learning and using academic skills. “Specific Learning Disorder” has become the umbrella term for mathematics, reading, and written expression disorders in the updated DSM-5. The DSM-IV previously classified these as separate diagnoses. Instead, these disorders are now housed under one diagnosis with added specifiers (e.g., specific learning disorder with impaired reading).

Speech-Language Therapist or **Speech Language Pathologist** is a clinician who specializes in the evaluation, diagnosis, and treatment of communication disorders, cognitive-communication, voice disorders, social communication, and swallowing disorders.

Speech-Language Therapy is provided with the goal of improving an individual’s ability to communicate. This includes verbal and nonverbal communication. The treatment is specific to the individual’s need. Spoken Language (also referred to as expressive and receptive language) is the use of verbal behavior or speech, to communicate thoughts, ideas and feelings with others. Involves learning many levels of rules - combining sounds to make words, using conventional meanings of words, combining words into sentences and using words and sentences in following rules of conversation.

Stereotyped Behaviors refer to an abnormal or excessive repetition of an action carried out in the same way over time. May include repetitive movements or posturing of the body or objects. **Stereotyped Patterns of Interest** or **restricted patterns of interest** refer to a pattern of preoccupation with a narrow range of interests and activities.

Stimming or “**self-stimulating**” behaviors, are stereotyped or repetitive movements or posturing of the body that stimulate one’s senses. Some “stims” may serve a regulatory function (calming, increasing concentration or shutting out an overwhelming sound).

Subclinical Seizure, see **Seizures**.

Supplemental Security Income (SSI): An income-based federal program for individuals with disabilities.

Supported Employment: Work done by people with cognitive, physical, or emotional challenges involving an adapted environment or additional support staff.

Symbolic Play is where children pretend to do things and to be something or someone else. Typically develops between the ages of 2 and 3 years. Also called make believe, pretend or imaginative play.

Syndrome is a set of signs and symptoms that collectively define or characterize a disease, disorder or condition.

T

Tactile Defensiveness is a strong negative response to a sensation that would not ordinarily be upsetting, such as touching something sticky or gooey or the feeling of soft foods in the mouth. Specific to touch.

Task Analysis is the process of breaking a skill down into smaller steps.

TEACCH is a therapeutic approach broadly based on the idea that individuals with autism more effectively use and understand visual cues.

Theory of Mind refers to the cognitive ability to recognize that one’s feelings, perceptions, beliefs, and desires differ from those of others. Theory of Mind enables us to assign “state of mind” to others and react and respond to feelings.

Tonic-clonic Seizure, see **Seizures**

Typical Development describes physical, mental, and social development of a child who is acquiring or achieving skills according to expected time frame. A child developing in a healthy way pays attention to voices, faces and

actions of others, showing and sharing pleasure during interactions and engaging in verbal and nonverbal back-and-forth communication.

U

V

Verbal I.Q. describes the score resulting from various tests involving verbal tasks, such as understanding written material and answering general knowledge questions.

Visual Spatial Skills are those skills that are nonlinear, sequential, and are dependent upon processing shapes, colors and pictures, rather than language.

Verbal Behavior is a method of **Applied Behavioral Analysis** (ABA) for teaching children with autism, based on B.F. Skinner's description of the system of language.

Vestibular System refers to the body's system for maintaining equilibrium.

W

X

Y

Z

WV Team Autism 2016-2017 Membership

Individual	Affiliation
R. Greg Bartlet	RESA 1
Barbara Becker-Cottrill	WVATC – Marshall University
Delia Ben Chabaanne	Mercer County Schools
Lashanna Brunson	WVU Center for Excellence in Disabilities
Angela Bryson	WVATC – Marshall University
JoDonna Burdoff	WV DoE
Naomi Creer	Parent
Allison Close	Parent
Jason Deussenberry	NECCO
Jeanie Elkins	Parent
Kristy Ellison	Diversified Assessment and Therapy Services
Marc Ellison	WVATC – Marshall University
Tammy Haffer	Parent
Shelby Haines	Marshall County Schools
Jim Harris	WVATC – Marshall University
Tina Hatfield	WVATC
Lesa Hines	RESA 7
Pat Homburg	WV DoE
Brenda Lamkin	WV Parent Training and Information
Erin Lash	WVATC – Marshall University
Cindy LeGrand	WV Birth to Three and Bright Futures Learning Services
Jennifer McFarland Whisman	Assistant Professor – Marshall University
Jill McLauray	Bright Futures Learning Services
Dr, Susannah Poe	Intensive Autism Delivery Clinic & WVUCED
Karen Randolph	WV Northern Autism Community Chapter
Claudia Raymer	Ohio County Family Resource Network
Pam Roush	WV Birth to Three
Mary Ann Sullivan-Scott	RESA 8
Deena Swain	RESA 5
Diana Whitlock	WVDoE-OSE, Coordinator of Autism Spectrum Disorder
Beverly Winter	Raleigh County Schools
Mel Woodcock	WV Birth to Three
Sheila Zickefoose	WV Early Childhood Training Connections and Resources and WV Birth to Three



This is a product of West Virginia Team Autismautism Spectrum
Working Together for West Virginians with ASD and their Families